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S. HRG. 103-154

REAUTHORIZATION OF THE CDC BREAST AND CERVICAL CANCER MORTALITY PREVENTION PROGRAM

Y 4.L 11/4:S.HRG.103-154

Reauthorization of the CDC Breast a...

HEARING

BEFORE THE

SUBCOMMITTEE ON AGING

OF THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

ONE HUNDRED THIRD CONGRESS

FIRST SESSION

ON

EXAMINING PROPOSED LEGISLATION TO AUTHORIZE FUNDS FOR THE CENTER FOR DISEASE CONTROL'S BREAST AND CERVICAL CANCER MORTALITY PREVENTION PROGRAM

JULY 15, 1993

Printed for the use of the Committee on Labor and Human Resources

OCT 13

U.S. GOVERNMENT PRINTING OFFICE

70-556 WASHINGTON : 1993

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0-16-041339-7

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REAUTHORIZATION OF THE CDC BREAST AND CERVICAL CANCER PREVENTION PROGRAM

THURSDAY, JULY 15, 1993

U.S. SENATE,
SUBCOMMITTEE ON AGING, OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The subcommittee met, pursuant to notice, at 10 a.m., in room SD–628, Dirksen Senate Office Building, Senator Barbara A. Mikulski (chairman of the subcommittee) presiding.

Present: Senators Mikulski and Wellstone.

OPENING STATEMENT OF SENATOR MIKULSKI

Senator MIKULSKI. Good morning, everybody.

I'd like to convene this hearing of the Subcommittee on Aging of the Labor and Human Resources Committee. And there are those who might ask, well, what does the Breast and Cervical Cancer Mortality Prevention Act have to do with aging? It has been the intent of this Chair, with the concurrence of Senator Kennedy, to really take this subcommittee into focusing not only on the specific issues of aging, but the life cycle issues related to aging and what we can do to prevent those diseases that then determine one's lifespan and life cycle.

We are in the course of the Clinton administration not only redefining government, but redefining the way subcommittees act and think. We also hope to redefine the way health care is being done, with greater focus and attention on prevention and early detection and screening.

That is why today we are holding a hearing on the Breast and Cervical Cancer Mortality Prevention Act. This is indeed a very, very important hearing because of what I know it has meant to so many people.

I'd like to start by thanking all of you for coming here today to review where we have been and where we are going to go on this early detection and screening program. I think you would all agree this is an important day for millions of women in this country. I want to thank the witnesses who are here today, some of them from many miles, disrupting their lives and taking time off work to be with us. But do you know what? I'll bet the sacrifice that you make to be here today is one you would do anyway to help anyway to help us make sure that we are out here, using a public investment to save the private lives of American citizens.

It is no secret that I am extremely proud to have been associated with the enactment of this legislation. One might say I have been the "Founding Mother" of this legislation. What I am most proud of is the fact that we will be concerned in Washington not only about cutting the deficit, but also about cutting the death rate.

Most of the people here today know the hard facts about breast and cervical cancer. Breast cancer strikes more than one in eight women at some point in their lives. Cervical cancer strikes about one in 100. Both strike hardest on older women, women of color, and women of limited income—the people in our society with the least resources.

In total, more than 180,000 new cases of breast cancer will be detected this year in this country. Some 46,000 women will die from this disease. And although it strikes fewer women, cervical cancer is no less important. About 14,000 cases of cervical cancer will be diagnosed this year. Four thousand mothers, daughters, relatives and friends will die from this disease.

Sadly, we do not know either the cause of breast or cervical cancer although we have succeeded in almost doubling the funding at NIH over the last 5 years into these two major killers of women. And the request for 1994 will continue to sustain that effort. Maybe now that these diseases are getting the attention they deserve, I happen to believe that the diseases have gotten attention, but we want to make sure women get the attention in terms of our lives and our lifestyles.

My brilliant staff has written for me a 10-page statement which I am going to put into the record, because I will end up sounding like a witness on this issue. And I am going to ask unanimous consent, which I will agree to myself, to put it in the record, so we can go on to taking the testimony.

This is going to be a hearing where we listen to both the professionals in the field as well as the grassroots people who put it together. This program has meant a lot to me as I have travelled in my own State of Maryland, and I am very proud of the fact that Maryland won one of the grants on a competitive basis to be doing this; that Federal funds have been used to help 12,000 Maryland women get the attention that they need in terms of this early detection.

The other day, I was in Western Maryland, which has one of the highest poverty rates in the State of Maryland. Although the people are poor, they are indeed proud. Many of them are not on Medicaid and yet fall well below the cracks to have either health insurance on their own or to be able to afford primary care.

The public health officer up there told me how over 300 women in Western Maryland had the opportunity for this early detection and screening because of this grant and the innovative techniques to reach out to rural women.

A few weeks before that, I was in Baltimore City with the YWCA who, through their innovative project, "ENCORE," show that you not only have to provide a resource, but you have to create the infrastructure for people to take advantage of the resource, and that we have to deal not only with the issues, but we have to deal with the fear around those issues.

The YWCA is to be congratulated for their innovative outreach to people of all colors, but I would like to particularly congratulate them on their outreach to women of color, and I know we will hear about that.

And last but not at all least, right at that diner where I took the First Lady of the United States of America to listen to the issues around health insurance reform, the women who work behind that counter, who end up at the end of the day with bad backs, varicose veins, and no health insurance, have told me how they were able to take advantage of the Baltimore program to at least be able to see if in their lives they can't stop stress, they can't stop the problems that they face, they can't stop all the difficulties that come with being a single mother, but what they can do is to make sure that if they have a disease, they will have the resources to help themselves.

So today I am going to hear what is happening in other States. I am pleased with the Maryland program, and we look forward to hearing about why we need this program and how now we can benefit from the lessons learned.

I would also like to insert statements by Senators Gregg and Hatch at this point.

[The prepared statements of Senators Mikulski, Gregg, and Hatch follow:]

PREPARED STATEMENT OF SENATOR MIKULSKI

I'd like to get started by thanking you all for coming here today to 'review where we have been and where we have to go on this most important piece of legislation, the Breast and Cervical Cancer Early Detection Program. I think you will all agree that this is an important day for millions of women in this country.

I want to particularly thank the witnesses who came here today, some of them from many miles—disrupting their lives, taking time off work and so forth—to be with us.

But you know what? I bet they would make this sacrifice any day we asked, because, like me, they know the importance of this legislation. Like me they have seen the faces—the grateful faces—of the women across America who have literally had their lives saved by this program.

It is no secret that I am extremely proud to have been associated with the enactment of this legislation. I suppose I've been involved with issues that had a bigger price-tag, that got more press and so forth, but none have been more important to me than this. And that's because nothing is more important than preventing the needless loss of life.

I have often said that while many people in this town are obsessed with cutting the deficit, I'm obsessed with cutting the death rate. And I'm proud of that.

And even for those who say that the budget concern should come first, I'm here to say this law more than pays for itself, as cancers detected early cost thousands less to treat than cancers detected late. And anyway, I feel sorry for anyone who tries to put a price-tag on the lives of women in America.

Most of the people here today know the hard facts about breast and cervical cancer. Breast cancer strikes more than 1 in 8 women

at some point in their lifetimes, cervical cancer strikes about 1 in 100. Both strike hardest on older women, women of color, and women with limited income—the people in our society with the least defenses.

In total more than 180,000 new cases of breast cancer will be detected this year in this country, and some 46,000 women will die from this disease. And though it strikes fewer women, cervical cancer is no less important. Almost 14,000 cases of cervical cancer will be diagnosed this year, and 4,000 mothers, daughters, relatives and friends will needlessly die from this disease.

Sadly, we do not know the cause of either breast cancer or cervical cancer, though we have succeeded in almost doubling the funding provided to the National Institutes of Health over the last 5 years for research into these two major killers of women. And the request for 1994 includes the largest increase ever. Maybe now that these diseases are getting the attention they deserve we will learn more about how to prevent them from occurring.

Even though we don't know how to prevent these types of cancer, we do know what we need to do to save many of these lives. The problem is we don't do what it takes. A woman's best defense is regular screening using mammography, clinical breast exams and self examination, Pap tests and pelvic exams. If all women over 18 had and regular Pap tests, cervical cancer deaths would be reduced to zero. And if all women over 40 were regularly screened using mammography, we would cut breast cancer deaths by almost one-third.

All women should hear this message, and as the National Cancer Institute has urged, think of these tests as a "Once a Year for a Lifetime1, routine.

Later we will be hearing from people who have been working with this program and making a difference. I'm particularly pleased that the YWCA Encore Plus Program which got started in Maryland is here today. I had the opportunity to visit those folks back in May, and let me tell you they are way ahead of us. They have been concerned about these issues for 17 years and we have much to learn from their innovative know-how. They've got the people who can show us all how a public and private partnership can work to save lives, not only in Maryland, but all across America.

And when the United States of America wants to dial 911, so that the women of America can have 411 information, who better to call than the YWCA?

We need to be crystal clear on this next point. This law has provided a start in our battle against these dreaded diseases, but we have a very long way to go. I remain deeply disturbed by the tragic and unnecessary loss of life we witness every day from these cancers. America's women deserve more!

Right now only 12 States have comprehensive programs providing screening for breast and cervical cancer to women m need. But that word "comprehensive" is very misleading, since those States are providing only a small fraction of the annual screenings needed. For example, Michigan provided 18,000 screenings last year but has 240,000 women over 40 years of age with income below the poverty line.

Another 18 States are now in the capacity building stage—which means they have even further to go.

This, of course, leaves 20 States with no program whatever. So millions of women remain at risk.

That's why, while I'm proud of the progress we've made and the lives we've saved, it is way too soon to rest on our laurels. This effort is not yet an accomplishment, it is a work in progress.

And we need to do more than just add more States and screen more women. We - also need to do what it takes to make this program as good as it can be. That means:

—We need to look at covering more diagnostic treatments.

—We need to assure follow-up treatment.

—We need to assure top quality screenings.

We also need to assure that we are making progress on the kind of research needed to assure that this program is working, that it is reaching the women who need it most.

And when answering the question about what we are accomplishing we must remember that this program is much bigger than the number of women screened or cancers detected early as a result of the direct services provided by this legislation. As important as that is, it is only one way to should answer the question of this program's effectiveness. That question should also be answered using a much higher standard. The standard is: are all the women in America getting these essential tests on a regular basis.

Above all, no woman should ever turn away from the decision to have one of these screenings because of a lack of funds or access to these services. Our job today is to learn more about how we can reach that vision as soon as possible. America's women deserve no less.

One final point, as we await the President's proposals for national health care reform, I am happy to say that comprehensive reproductive health services including these screening services will be included. I have that from the White House. But we are a long way off from full implementation of that plan, and we need to continue to build the groundwork for an effective delivery system now.

Again, I welcome each of our witnesses, and I look forward to your testimony.

Prepared Statement of Senator Gregg

Madame Chairman, I want to begin by commending you on the work that you have done toward preventing breast and cervical cancer in this country. You are a recognized leader in the Senate on these problems, and I know that you were one of the authors of the statute that we are considering here today, the Breast and Cervical Mortality Prevention Act of 1990. I congratulate you on your tremendous accomplishments and concern.

The two cancers that we are here to discuss today, breast and cervical, are among the greatest scourges in our country. According to the Centers for Disease Control and Prevention, in this decade, two million women will be diagnosed with breast or cervical cancer, and over a half-million of them will die.

Those are terrible statistics. And yet, we have made great progress against breast and cervical cancer. Death rates from both

diseases have fallen dramatically since the 19505. In the area of breast cancer, science has made huge strides in treatment—new methods of radiation, chemical, and surgical treatments—better knowledge about the natural history and the epidemiology of the disease. The survival rate from breast cancer has increased dramatically.

Likewise in cervical cancer, we have a better understanding of the causes of the disease, and we have better ways of dealing with the cancer when it is discovered.

We are also better able to prevent these two diseases from killing women. For both breast and cervical cancer, early detection is the key to survival, and science has new and better methods of early diagnosis. For breast cancer, we now have mammography, which can find tiny tumors, smaller than a pea, that are not detectable on physical examination. Thanks in part to mammography, the average size of breast cancer tumors in this country has declined since the mid-1970's. Other new detection methods, like magnetic resonance imaging, are now coming on the scene.

But with all the progress we have made, we still have a long way to go. This year, about 46,000 women will die from breast cancer in the United States, and 4,400 women will die from cervical cancer. The real tragedy is that many of these deaths could be prevented if the disease were detected early. For example, the 5-year survival rate for breast cancer, found when it is still in the localized stage, is 93 percent.

Deaths from cervical cancer, although far fewer than the number of deaths from breast cancer, are just as tragic because the vast majority are completely curable if they are found in their earliest stage.

The CDC National Breast and Cervical Cancer Early Detection Program was created through the 1990 Act. It has begun to make progress in helping disadvantaged women get screened for these diseases. As of July, 1992, a year ago, over 13,000 women had been screened for breast cancer, and over 20,000 had been screened for cervical cancer through the Program. Hundreds of cancers have been detected. If the CDC program did not exist, some of those cancers might not have been found until it was too late.

I applaud the CDC Program and the work that it is doing. One of the Programs's greatest accomplishments, in my view, has been the collaboration it has pulled together with other organizations, like the American Cancer Society, the AARP, the YWCA, and others.

I plan to support the reauthorization of the CDC Program, but I would like to take a moment to voice some concerns. Perhaps the witnesses could respond to them.

While I do see the obvious value of programs like this one, I also have reservations about how far Congress should go in funding categorical programs that are directed toward preventing one or two diseases at the level of the individual. When I think about these programs, I always remember that great Chinese proverb, "Give a man a fish and you will feed him for a day. Teach a man to fish and you will feed him for a lifetime. "I worry that we are spending too many federal dollars giving fish and not enough dollars on teaching to fish.

Let's be clear about the CDC Program. The Federal Government (with the help of the States) is providing direct medical services to individuals. This is public health at the "retail" level. The money is being used largely to purchase individual mammograms and individual pap smears.

I wonder whether this is the most effective way for the Federal Government to fight these two diseases. It might be more effective to spend more money at the "wholesale" level—to create more awareness of the need for screening—to create demand for preventive services—and to educate.

I am especially concerned when I see that the House wants to graft other, unrelated preventive services onto the CDC Program—services for high blood pressure and high blood cholesterol. In my opinion, that could be a great mistake. For one thing, it could dilute the value of the CDC Program.

Madame Chairman, I have another concern. In my view, programs such as the Early Detection Program should be periodically evaluated for efficacy and cost-effectiveness. The number of Federal dollars available to us in the Congress is always limited, and they are going to be more limited in the future. I think we must be sure that we are spending those dollars in the most effective way.

Here, our goal is to prevent deaths from two terrible cancers. I am in strong support of that goal. But I want to be assured that every single dollar that we spend saves the maximum number of lives. I look forward to seeing the evaluation report from the Secretary that, I understand, was cleared yesterday and will be sent to this committee in the next few days.

It makes no sense to put more federal funds into this program unless we know whether the previously-appropriated funds were used as intended, and whether they were potentially effective in preventing cancer deaths. By the end of FY 1993, we will have spent over $150 million. That is a lot of money. If all that money were spent on screening tests, at $100 per test, that would be enough money to screen 1.5 million women for breast and cervical cancer.

For fiscal year 1994, the President has asked for an increase of $14 million for the CDC Program. I am inclined to support that, but not until I am confident that the money is being used wisely and effectively to prevent breast and cervical cancer.

One final point, Madame Chairman. As I looked over the provisions of the Act, I noticed that there is no requirement for the Secretary to consider the number of deaths from these two diseases in the applicant state. In other words, states with low mortality rates could be funded before States with high mortality rates. Indeed, that has happened over the past few years.

I understand that CDC is now planning to take disease mortality into account when it scores new grant applications. However, the extent of the disease burden in the applicant State will comprise only ten of 100 points on the scale used to evaluate applications.

One of the oldest tenets in public health is that scarce resources should be directed to where they will do the most good. In the case of these grants, they should be sent to the States that have the greatest desire and capacity to administer them, to the States that have the largest populations of eligible recipients, but also to the

States whose inhabitants suffer the most from the diseases we are trying to prevent. When Willie Horton, the famous bank robber, was asked why he robbed banks, he replied, "Because that's where the money is." Well, we ought to be sending prevention dollars to where the mortality is.

This subject is near and dear to me, because my own State of New Hampshire has an inordinately high mortality rate from both of these diseases. Our breast cancer mortality rate is the seventh highest in the nation. According to the experts at the New Hampshire Division of Public Health Services, much of that mortality is due to a failure of proper screening. New Hampshire also has a very high mortality rate from cervical cancer among white women. That also, is probably due to inadequate screening.

I am very tempted to suggest that Congress amend the statute to require the Secretary to take disease mortality into account when she awards grants, and mortality should make up more than just 10 percent of the decision. Mortality should be one of the major factors used to select recipients.

Madame Chairman, I thank you and I look forward to the testimony of the witnesses.

PREPARED STATEMENT OF SENATOR HATCH

Senator Mikulski, I would like to begin by commending you for holding this hearing today and for your sponsorship of the landmark "Breast and Cervical Cancer Mortality Prevention Act" almost three years ago.

Your work to advance women's health is legendary and will benefit the many millions of American women who will face cancer at some point during their lifetimes.

Although we have made progress in the prevention and cure of breast and cervical cancer, I believe there still remains much to be done.

As I noted at a recent full Labor and Human Resources Committee session, when I joined the Committee in 1977, one out of each 13 women in the United States was diagnosed with breast cancer each year. Last year, we were all shocked to learn that the rate had risen to one in nine.

The eradication of breast cancer needs to become a national priority, and I am pleased to join in the efforts of the subcommittee.

In my home State of Utah, breast cancer is the leading cause of female cancer death. This year alone, 196 Utah women died from breast cancer, and 700 new cases were reported.

Despite the overall favorable health indicators in Utah, women in my state who are diagnosed with breast and cervical cancer do not have better survival rates than the rest of the United States. They join the 46,000 breast cancer victims and 4,000 cervical cancer victims who die annually in this country.

We need to prevent the suffering of women, families, and friends as much as we can through early detection. I would like to see mortality rates become survivor rates.

That is where the reauthorization of the Center for Disease Control and Prevention's Breast and Cervical Cancer Prevention Program becomes so important. The CDC program creates a partner-

ship between CDC, States, and Federal, voluntary, and community-based organizations who will work together to improve detection, control, and follow-up treatment of breast and cervical cancer. Through education, expansion and progression, CDC is attempting to increase early detection and target women at risk.

In July of this year, Utah joined with the approximately 40 other States who have expressed interest in funding under the program. Our participation in this program will increase the accessibility and quality of breast and cervical cancer screening, follow-up, and treatment services for Utah women.

Utah hopes to increase the percentage of women receiving screening mammograms and Pap tests, thereby reducing the cancer mortality rate. In particular, it will target those who are low-income, undereducated, or in rural lareas and who lack health care services and are undoubtedly more often the victims of undetected breast and cervical cancer. Utah participation in this preventive program will bring progress and expansion to women's health care services, a need that the Breast and Cervical Cancer Prevention program is fulfilling and extending nationwide. I believe that when the services provided under the program become available to all women in each of the 50 States and in all federally-supported clinics we will be able to decrease the high breast and cervical cancer mortality rates.

In particular, I intend to work to see that all federally-supported clinics provide breast and cervical cancer screening and information. This is a critical health care need for all women in the nation. Certainly the government should do what it can to see that the goals of the Breast and Cervical Cancer Prevention program are carried out in federally-supported programs.

Again, I thank the Chair for holding this hearing today and for sponsoring this important legislation. I want to work with you and other members of the Committee as this reauthorization moves forward.

Senator MIKULSKI. Having said that, we would now like to turn to Dr. Stephen Wyatt, the director of the Division of Cancer Prevention and Control at CDC.

Dr. Wyatt, we welcome you, and we look forward to hearing from you about CDC's perspective, their views on this program and lessons learned in the first phase of operation. I would like to thank you and thank the men and women who work at CDC for being able to take that legislative initiative and, in a quick-step way, get it out to the communities.

So, Dr. Wyatt, why don't you proceed.

STATEMENT OF DR. STEPHEN WYATT, DIRECTOR, DIVISION OF CANCER PREVENTION AND CONTROL, CENTERS FOR DISEASE CONTROL AND PREVENTION, PUBLIC HEALTH SERVICE, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ATLANTA, GA

Dr. WYATT. Good morning. I am Dr. Steve Wyatt, director of the Division of Cancer Prevention and Control at CDC. I appreciate the opportunity to be here this morning and share with you an overview of the status of the implementation of the Breast and Cervical

Cancer Mortality Prevention Act of 1990 and CDC's excitement about the future of this important prevention program.

The numbers are staggering. In this decade, more than 2 million American women will learn they have breast or cervical cancer, and approximately 500,000 women are expected to lose their lives. The early detection of these cancers combined with appropriate and timely follow-up remains the single most effective method to ensure more treatment options, improve survival, and decrease mortality.

We applaud the efforts of the research community to continue to diligently search for a way to prevent cancer from occurring, but until a "magic bullet" is found, we must continue to take forward the message about the value of screening.

The problem is this. Screening rates in the United States are unacceptably low. National data for 1991 indicate that only about 58 percent of women age 50 and older had received a mammogram in the past 2 years, with the proportions being far lower for women of low income. And, in spite of the proven benefits of the Pap test for over 40 years, a significant proportion, or approximately 21 percent, of women are not being screened on a routine basis.

There are many reasons why women are not being screened. Among the most common are the cost of the screening test, not being informed about the difference early detection can make, and lack of provider recommendation for screening. Experts agree that a comprehensive, coordinated public health approach is necessary to reduce mortality related to these cancers. A national infrastructure is essential to support the various complex elements necessary to guarantee all women at risk access to high quality screening and follow-up services. Simply removing the cost barrier will not completely solve the problem, though, as our colleagues in Sweden and the United Kingdom have learned.

Congress acknowledge the life-saving potential of screening, mammography and Pap testing and the value of a comprehensive approach when it passed this Act in 1990. This law forms the foundation for a long-term, comprehensive strategy by authorizing CDC to establish breast and cervical cancer early detection programs in partnership with State health agencies. Under this authority, CDC and the States work together to assure access to screening and referral services for women at risk, advise women of the value of early detection, improve the skills of health care professionals to assure high-quality screening, exams and tests, establish surveillance systems for program planning and evaluation, and establish State cancer coalitions.

CDC supports the development of an early detection infrastructure through a two-tiered funding mechanisms. States with an established infrastructure are funded by a comprehensive program, including the provision of screening services for eligible women. These awards range from $2 to $5 million each. States that are not yet ready to provide comprehensive program services are funded at much lower levels for capacity building efforts to assist them in developing the service delivery, education, quality assurance, and surveillance infrastructure required for an effective, comprehensive early detection program.

In fiscal year 1992, 30 States received funding—12 States for comprehensive programs and 18 States for capacity building pro-

grams. This fiscal year, we expect to fund up to 36 States—18 for comprehensive programs and 18 for capacity building. These programs will provide an estimated 340,000 screenings for eligible women who would not have otherwise had access to these services.

In fiscal year 1994, with the President's budget request of $85 million, we expect to fund up to 39 States—21 comprehensive programs and 18 capacity building programs—and provide as many as 400,000 screening exams.

As of January 1993, CDC supported States have provided 31,105 screening mammogram——

Senator MIKULSKI. Dr. Wyatt, would you read those numbers very slowly, because I want the record to really show what we have done.

Dr. WYATT. I certainly will. As of January of this year, comprehensive States have provided 31,105 screening mammogram; 2,774 women have been referred for follow-up, and breast cancer has been diagnosed in 102 women to date.

For cervical cancer, 53,555 Pap tests; 7,813 women referred for follow-up; 3,071 women have been diagnosed with an early indicator of cervical cancer; invasive cervical cancer, which is a true failure of the system, has been diagnosed in 13 women.

Although the statute does not permit the States to use Federal dollars to provide treatment, States are required to establish follow-up systems to ensure treatment. States are committed to following the intent of the law and to assisting every women who has an abnormal screening exam with receiving timely and adequate follow-up. This is accomplished through a variety of innovative strategies with both the private and voluntary partners of the States.

Currently, over 1,305 screening sites participate in the 12 State programs. This compares to only 575 sites in 1992. This is an increase of more than 200 percent in only 1 year. States have strategically utilized a blend of providers ranging from traditional local health departments, Indian health service clinics, women's organizations, and Federally funded community and migrant health centers.

In addition to providing screening and follow-up services for eligible women, the law mandates the development of a supportive early detection infrastructure that will benefit all women in funded States. CDC fosters the development of public and provider education, quality assurance and surveillance activities to enhance the national public health infrastructure through collaborative efforts with the States, with professional organizations such as the National Medical Association and American College of Radiology, and voluntary partners such as the American Cancer Society, the YWCA, National Alliance of Breast Cancer Organizations, AARP, and the American Public Health Association. These programs are already making a difference.

Some evidences are the more than 2,900 public education programs that have been presented to high-risk women. Unique outreach efforts with community-based partners like the YWCA in Baltimore and Abilene are two examples of innovative strategies being used to reach the target population. Seven of the 12 States have enacted new legislation in support of breast and cervical can-

cer screening, and more than 440 organizations are currently collaborating with State health agencies in a broad range of early detection activities.

We have made tremendous progress under this program and are seeking a 3-year reauthorization. We must continue to enhance the firm foundation we have established for a concerted national public health strategy to save women's lives. The challenges are great. Almost 200,000 women will be diagnosed with these two cancers in 1993 alone, and more than 50,000 women will lose their lives this year. However, the benefits of early detection and an established infrastructure to support screening are proven, and they are currently the only tools we have to save lives.

The early detection of these cancers gives us the opportunity to make a life or death difference for thousands of women.

I'd like to take this opportunity to thank you, Senator Mikulski, for your vision in developing this historic legislation back in 1990, and I would be happy to answer any questions you might have.

[The prepared statement of Dr. Wyatt follows:]

PREPARED STATEMENT OF STEVE WYATT, M.D.

Good morning. I am Dr. Steve Wyatt, Director of the Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion of the Centers for Disease Control and Prevention (CDC). I appreciate the opportunity to be here this morning to share an overview of the status of the implementation of the Breast and Cervical Cancer Mortality Prevention Act and CDC's excitement about the future of this important prevention program.

First, I would like to thank you, Senator Mikulski, as well as the full Committee for your vision and role in developing this historical legislation in 1990.

BREAST AND CERVICAL CANCER EARLY DETECTION

Breast cancer is the most commonly diagnosed cancer among American women and is second only to lung cancer as the leading cause of cancer death. In this decade, more than two millions American women will be diagnosed with breast or cervical cancer and approximately 500,000 women are expected to lose their lives. Mortality rates for breast and cervical cancer are disproportionately high among women of low income. While the number of deaths from cervical cancer is not of the same magnitude as that of breast cancer, essentially all deaths from cervical cancer are preventable with full utilization of the Papanicolaou (Pap) test. We applaud the efforts of the research community to continue to search diligently for a way to prevent cancer from occurring, BUT, until a "magic bullet" is found, we must continue to take forward the message about the value of screening. Current research indicates that mammography screening for breast cancer can reduce mortality by approximately one-third through early detection and prompt initiation of effective treatment protocols. Despite the existence of this knowledge for more than a decade, national data for 1990 indicate that only about one-third of women age 40 or older had received a mammogram in the past year, with the proportion far lower for women with little education, women older than age 70, and women of low income. The early detection of cancers of the breast and cervix, coupled with appropriate and timely follow-up, remain the most effective methods to ensure more treatment options, improved survival, and decreased mortality. Similarly, in spite of the benefits of the Pap test, a significant proportion of women are not being screened on a regular basis.

Experts agree that a comprehensive, coordinated public health approach is necessary to reduce mortality related to these cancers. A national infrastructure is essential to support the various complex elements necessary to guarantee all women at risk access to high-quality screening and follow-up services. Simply removing the cost barrier will not completely solve the problem, as our colleagues in Sweden and the United Kingdom have learned. Women as consumers, health professionals, voluntary and community organizers and state and federal policy makers all play a vital role in successful cancer control; and collectively, this network has the skills and resources to enable all women to benefit from life-saving screening technology. Having such comprehensive cancer control models in place nationwide will provide

the impetus to help bring new and effective treatment and recovery mechanisms in a timely fashion to the women who need it most.

Congress acknowledged the lifesaving potential of screening services when it passed the Breast and Cervical Cancer Mortality Prevention Act of 1990. This law forms the foundation for a long-term, comprehensive national public health approach by authorizing CDC to establish breast and cervical cancer early detection programs in partnership with State health agencies. Under this authority, CDC and the States work together to:

—establish, expand, or improve screening services in communities or women at risk;

—deliver education programs that send the public clear, consistent, and culturally sensitive messages about the lifesaving value of screening;

—deliver education programs to physicians and other health care professionals to improve skills related to early detection;

—improve quality assurance measures to ensure adherence to standards and guidelines related to screening mammography and cervical cytology;

—establish surveillance systems that guide program planning and evaluation; and

—establish State cancer coalitions that include key public, private, and voluntary organizations to marshall resources and establish specific program objectives.

In fiscal year 1992, 30 States received funding—12 States for comprehensive programs and 18 states for capacity building to prepare for having comprehensive programs. In fiscal year 1993, we expect to fund up to 36 States—18 for comprehensive programs and 18 for capacity building. In fiscal year 1994, with the President's Budget request of $85 million, we expect to fund up to 39 States—21 for comprehensive programs and 18 for capacity building.

As required by the statute, those States with comprehensive programs expend not less than 60 percent of their grant funds for screening and follow-up services. As of January 15, 1993, 31,105 eligible women in 10 States had been screened by mammography; 2,774 women had been referred for follow-up; and breast cancer was diagnosed in 102 women; 53,555 women had been screened by Pap testing; 7,813 women were referred for follow-up; cervical intraepithelial neoplasia, an early indicator of cervical cancer was diagnosed in 3,071 women; and invasive cervical cancer was diagnosed in 13 women. These screening numbers are consistent with what would be expected during the initial stages of a large screening program.

Although the statute does not permit the States to use Federal dollars to provide treatment, States are required to establish follow up systems to ensure treatment. States are committed to following the intent of the law and to assist every woman who has an abnormal screening exam with receiving timely and adequate follow-up. This is accomplished through a variety of innovative strategies with private and voluntary partners.

All State grantees collect and report information on screening location, patient demographic characteristics, screening results, and diagnostic procedures. These data help state health agencies implement, direct, evaluate and monitor their screening programs; provide State legislators with data on the progress and results of the program; and direct and enhance CDC's efforts with program leadership and technical guidance. Additionally, each funded state establishes public/private cancer control coalitions which include State and local representatives from professional, voluntary, and community-based organizations. Unique outreach efforts with community-based partners, such as the Young Women's Christian Association (YWCA) in Baltimore and Abilene, are only two of many innovative strategies being used to reach the target population.

We have made tremendous progress under this program and are seeking a 3-year reauthorization to continue to expand the availability of these life-saving preventive services. I want to take this opportunity to again thank the committee and Senator Mikulski for your vision in developing this historic legislation in 1990. I'll be happy to answer any questions you or the other members may have.

Senator MIKULSKI. Thank you, Dr. Wyatt.

I am going to go through just a few of the questions. First of all, when you give those numbers and statistics, we all know that women and their families are behind them. I was interested in the fact that more women had been screened through the technology of the Pap smear for cervical cancer than women had been screened for breast cancer. One was at about 30,000 for breast can-

cer, and roughly 50,000 for Pap smears. How do you account for that, and what would be the lessons learned from that?

Dr. WYATT. I think one of the lessons that we have learned is that as programs start developing in the States, they have to go to service delivery entities that are easy to get to, first of all. And I think it is much harder for us to reach older women for breast cancer screening. That's the first point I would make. We know the value of screening in women 50 and older; 40 to 49 is controversial now. But for the Pap test, we are screening younger women as well.

So I think the lesson I would take away from this is that it is easier to keep younger women in the system and keep screening them for cervical cancer, but once folks leave the childbearing years and maybe stop seeing their ob or their gyn, then it is very difficult to bring them back into the system to start breast cancer screening.

Senator MIKULSKI. Dr. Wyatt, some of the questions I am asking are really as part of the groundwork for, hopefully, national health insurance reform. Is it your observation that for women, and particularly women of childbearing age, that their ob-gyn is their primary care physician and that therefore, when they go to their primary care physician for ob or gyn services, part of the routine is for a Pap smear, so it is part of the routine——

Dr. WYATT. Correct. That's a good observation.

Senator MIKULSKI. In terms of if one views, as I do, ob-gyn as one of the areas of primary care, that that is a routine test, just like taking blood pressure and so on. In other words, women are more likely to go and see their ob-gyn, but then when they have to find or be referred to, whatever, it involves another whole step to go and get the mammogram.

Dr. WYATT. That's correct. I think another point I would make is that as we all get older, we tend to lose contact with preventive health services. I think we tend to be seen for acute care.

I use the example that if you have arthritis, your rheumatologist many times becomes your primary care provider, and primary care providers, such as FPs or OBs, are much more likely to refer for screening for breast cancer, for example, as opposed to an internist.

Senator MIKULSKI. So, based on that, there are a lot of lessons learned such as, first of all, public education for the physicians; is that right?

Dr. WYATT. Correct. I think it is really important. We conducted a study in Rhode Island several years ago, and we found that a woman who had a recommendation from her provider for a mammogram was seven times more likely to receive a mammogram than a woman without a recommendation.

And another study is really striking. I am from Kentucky, and we conducted a study in the rural southeastern part of the State, Appalachia, and we found nine provider visits in a 3-year period prior to diagnosis for cervical cancer. All those were missed opportunities for the cervical cancer piece, and it is really a shame.

Senator MIKULSKI. As we redraft or re-look at this legislation, what lessons would you give us in terms of the focus on having physicians be aware of this? One of the things we have found in our work on women's health is that, one, women are not listened

to. Women listen to their doctors, but their doctors don't always listen to the women. And we believe there has to be a two-way channel of communication. The second is that, often, women's symptoms are minimized. And third, that there is not the referral, or the next step.

My internist, for example, talked to me many years ago about the need for, at that stage in my life, a biannual mammogram. Now I am post50, so it would be an annual mammogram.

So as part of public education, is this a key component? Do we need to flesh it out more?

Dr. WYATT. I think it is a key component. Physician referral is critical. And one of the things we have done at CDC nationally—that is the reason we have brought folks together—we have started working with NMA, with AMWA, with the American College of Physicians, which is an internal medicine group, and we are working with the AMA. We are looking at strategies nationally that can filter down to the local level, and I think it is important for us to do that. We parallel that with work with national organizations like the YWCA and AARP at the community level, but with providers it is critical that we continue to get the message to them with reminder systems for practices about screening.

Senator MIKULSKI. So, then, Dr. Wyatt, we don't need to change the legislation; we have the legislation here. But it is in the area of CDC and its administration of the program. I know the first phase was to get it up and running.

Dr. WYATT. That's right.

Senator MIKULSKI. Now, we really want to focus on the public education of both the people who use the service, but also the physicians, nurse practitioners and others; am I right?

Dr. WYATT. That's correct.

Senator MIKULSKI. Dr. Wyatt, as part of the Preventive Health Amendments of 1992, Title XV now requires that States participating in this program cover mammography under the Medicaid program, in order to stretch CDC dollars. How many of those 30 States currently receiving funding are now covering mammogram under Medicaid? Has that been a good approach?

Dr. WYATT. I think it has been. We have always required that the Federal funds that are appropriated each year are "payer of last resort" funds, basically; that States must work through the menu of options available to them before they start charging it out against the State grant.

The Medicaid requirement, we did some checking with when this was starting to be enacted a few months ago, and all of the States except one had on their books requirements for Medicaid to cover screening mammogram and Pap smears, and that that State is currently in the process of coming up to compliance. And we require the States to certify that they are in compliance with that amendment.

Senator MIKULSKI. In the President's budget for fiscal 1994, there is a provision for $85 million. The House authorizes $135 million. In your professional judgment, how much is really needed to run an effective program in all 50 States of the United States of America?

Dr. WYATT. It would probably be best if I provided that for the record; is that all right?

Senator MIKULSKI. Is it that you don't know, or you don't care to say because of OMB? Listen, I'll deal with Panetta. You deal with me. [Laughter.]

Dr. WYATT. We did some estimates, and we looked at the cost nationwide for covering every uninsured woman. The costs nationwide were somewhere in the range of $600 to $700 million annually. But that is probably unrealistic, because not every woman is going to be screened. So what we also did was we stepped back, and we looked at it from a compliance viewpoint of 50 percent and 40 percent and 30 percent, to help us reach the "Healthy People 2000" objectives. And we feel like in the neighborhood of $200 million would give us the ability to be able to go to every State.

Senator MIKULSKI. I understand. Now, we also understand that under the law, an annual report is required, and we haven't seen that. What is the status of those annual reports?

Dr. WYATT. We take the annual reports very seriously. We commit staff time to them, and they are very important for us because they capture what the States are doing. The reports have been going through the clearance process, which is a lengthy clearance process, as you know, within the Department, and we learned this morning that the 1991 report has been cleared and is on its way to Congress at this point.

The 1992 report is also wandering through the clearance process at this point and hopefully will be cleared soon.

Senator MIKULSKI. So the reports were done, but they have not been cleared?

Dr. WYATT. Correct.

Senator MIKULSKI. I appreciate that.

Now, Doctor, before I wrap up my questions to you, what would you say were the important lessons learned over the last 3 years, and what problems have you had to overcome, and what changes would you recommend to us from a statutory perspective, and what changes do you intend to do from an administrative perspective—essentially, lessons learned.

Dr. WYATT. I think the first point I would make is that the program is a comprehensive program. I think that is very important. Just spending the money for screening is not the answer, and we see that over and over again with programs like immunization. I think we have to have the infrastructure in place that supports screening, and that is what this program is all about.

That's probably the most important lesson learned. We have seen how valuable it is to bring partners like the YWCA to the table, the American Cancer Society, AARP, the Breast Cancer Coalition in many States. That is an important process for this program, and it has really served us well in the first few years.

I think one challenge is in the treatment area. Since the statute does not permit the provision of treatment services from Federal dollars, the States are often called upon to beg, barter or steal for treatment dollars, and they have been successful; they have been doing that. But that is a challenge, and it will continue to be a challenge.

The other area of concern for us is in the area of age guidelines for screening for breast cancer, specifically.

Senator MIKULSKI. So, Doctor, I gather what you are saying is that this has been an important program, and it has been an important first step, and so far, so good. But what we really need is a national health insurance reform program so that all women have access first of all to health care; then, second, whoever is their primary care physician becomes the medical manager to ensure that women get screening, and that this type of screening would be provided as part of the preventive work, and then, therefore, also through the universal access, that there would be funding for the follow-up treatment, some of what might not be breast cancer but what is detected as a tendency for fibroids or many other things, because other things that are detected may be things that could contribute.

Am I correct?

Dr. WYATT. I think that should national health care insurance or health care reform include a basic benefits package that includes screening mammography and Pap tests—and I would hope that it would—I think the lesson I would take away from that, though, is to come back to the point of the infrastructure surrounding the screening. We have to continue to support State health departments and the private and voluntary sector to make sure that folks know about the value of the screen tests, that physicians are indeed recommending and referring, and that the quality is there. That is a key point.

I think one of the things we can hang our hat on in this program is that the quality assurance aspects in the States are very strong. We require ACR accreditation, and that is really important so that when the woman goes in for screening she knows that she is getting a good screening exam.

Senator MIKULSKI. Thank you.

The Chair would like to acknowledge the fact that Senator Paul Wellstone of Minnesota has joined us. Senator Wellstone, as you know, is one of the Galahads of the U.S. Senate. He has consistently worked, when I was the only woman in the Senate, and now with our addition, continues to be very supportive of this issue. Senator Wellstone has been under tremendous strain these last couple of weeks because of the terrible flooding.

We welcome you, Senator Wellstone. Any opening statement you have will be included in the record. Do you have any questions for Dr. Wyatt?

Senator WELLSTONE. No, Madam Chairman. I have no opening statement, and I'd like to continue to go forward with the testimony.

I did want to just build on two points that the two of you made. One, Madam Chair, it is just crystal clear to me that whatever universal health care coverage or national health insurance legislation we pass, that the package of benefits must be very heavily tilted toward preventive health care, with really creative ways of delivering care out in the communities where people live. I think that is crystal clear.

The mere fact that the benefits are there doesn't necessarily mean that you get them out to people, and I think that's one of the things we have learned.

The only other thing I wanted to mention was that Minnesota was one of the eight original States to receive a grant, and Dr. Jonathan Slader and Jane Kornin have been very involved with that. And from all reports I have received, it has been a very creative program that has reached some 16,000 to 17,000 people.

We live in a grassroots political culture, and Senator Mikulski and I met years ago—she doesn't actually remember this, but I invited her to Northfield, where I lived and taught at a college. Her background was community organizing, and I was organizing in rural areas, so I think we both have a commitment to making programs work out on the streets, whether they be streets in the city or streets in small-town, rural America. So those were some of the original demonstration models, and I think Minnesota-if I could be a Minnesota chauvinist for a moment—is a really good example of making it work.

Senator MIKULSKI. We'll call it a "booster."

Senator WELLSTONE. You can call it "booster." I think that's better.

In any case, thank you.

Senator MIKULSKI. Dr. Wyatt, there are many questions that we could ask you, but I think we have covered this ground today, and we are anxious to move to reauthorization. Again, we would like to thank CDC and its professional staff for both implementing the program, and for also follow-through on what we had intended, which was outreach to organizations to begin to educate women themselves.

Would you please thank the people at CDC in my behalf and our colleagues, for really following through on the legislative intent?

Dr. WYATT. I certainly will. Thank you, Senator.

Senator MIKULSKI. And maybe that's why we aren't getting a lot of press. If you had really goofed up and so on, and we were going to go through some type of midsummer hazing, that gets a lot more media.

Dr. WYATT. This is much nicer.

Senator MIKULSKI. Thank you very much.

Now we would like to turn to a panel of witnesses who will give us the perspective of the community groups and individuals who worked with the CDC in the outreach that is critical to the operation of the program.

I would like to call forward Ms. Lillian Brown, of Baltimore, MD, a citizen who participated in the program; Alexine Jackson, the vice president of the YWCA; and Vicky Rakowski, the vice president for cancer control of the American Cancer Society in Michigan.

We believe that one of the best parts of any hearing is where the people who are most affected have something to say. And we know that very often, programs that have been passed have been trickled down and that by the time they get out into the community, the community doesn't know about it, and there is no way to get the community there.

We would like to hear about your experiences, and we would first like to turn to Ms. Lillian Brown, who has been very key in this effort.

Ms. Brown, I met you at the YWCA in Baltimore, and you spoke to me so eloquently about how you got into this and why you stuck with it. So, could you share with us your experience?

STATEMENTS OF LILLIAN MAE BROWN, BALTIMORE, MD; ALEXINE JACKSON, VICE PRESIDENT, YWCA OF THE USA, WASHINGTON, DC, AND VICKY RAKOWSKI, VICE PRESIDENT FOR CANCER CONTROL, AMERICAN CANCER SOCIETY, MICHIGAN DIVISION, LANSING, MI

Ms. BROWN. Thank you, Senator Mikulski, for inviting me here today.

My name is Lillian Brown, and I am very honored to be here. It is an honor as well as a privilege that God has allowed me this opportunity to be here today to tell you a little bit about how I learned about the importance of mammogram.

I live in East Baltimore, at 1500 North Caroline Street. I have three adopted daughters; I have three biological children; I have raised 61 foster children for the State. In my home now, I have three adopted children—a 15-year-old, a 10-year-old, and an 8-year-old. All the children I have had down through the years have been kids with special needs. So you see I have lived a full and happy live, and I have been pretty healthy.

Now, last October, at the age of 59, I had never had a mammogram. I was at my doctor's office, and she always pushed me to get a mammogram. I said, "I can't get one," and she asked, "Why?" I said, "I don't have any money." I have been a widow for 5 years, too young for Social Security and too old to get a decent job. And my insurance is just for if I am hospitalized, and it doesn't cover mammogram.

So she said, "Let me see what I can do." A few days later, I got a phone call from a lady at the YWCA by the name of Ms. Linda Behsudi. I had heard so much about these mammogram, and I was really afraid. She talked to me a little bit, and I said, "Well, I've got to go on a trip, but put me down anyway, and pick me up Monday morning. But I am really afraid."

She said, "Well, I can't tell you what to do, but it is best to get it."

And I am so glad today that I met the lady from the YWCA.

Senator MIKULSKI. Where is the lady from the Y?

Ms. BROWN. Ms. Linda Behsudi is responsible for me being here today; she also brought me here today.

Senator MIKULSKI. Please stand up. There she is.

Ms. BROWN. And I had never really thought about breast cancer affecting me. You pray, you believe, and you trust in God you will always be healthy, but that's not true; we all have trials and tribulations, we all get sick. And that is why God has the doctors here to find out what is wrong with us.

So I went and got the mammogram, shaking, along with 12 other women. We went to John Hopkins to the oncology clinic. I was shaking, so afraid, my heart in my throat. But by having Ms. Behsudi and the other 12 women to walk through this process with

me, it wasn't anything. I got the mammogram, and everything I heard was false. It didn't even hurt at all.

So I got the mammogram, and now, each time—once you go to the hospital and get set up, when it comes time for your next mammogram, they will notify you.

I did not know at the time where to go to find out about the mammogram, until I met Miss Linda, the lady from the YWCA. They made all the arrangements. She spent time with me on the telephone. They came and picked me up with transportation. And over there, I learned a lot. We were taught how to do breast examination, and we learned all about mammogram from the teachers, and we learned how to go and get it taken care of early. We watched videos on mammogram. It was just a very rewarding situation.

I am glad I sacrificed, like you said; I am glad I did. If I had to do it over again, I would have sacrificed five times in order to help somebody in the process. By helping somebody else, I am also helping myself. And in order to help save somebody else's life, you just might save your own.

If anybody would ask me now, I would give them the information that I have, and then I would tell them to call the Y and speak to Miss Linda, and she would tell you all that I haven't told you about how to do it.

I know that the Y has always helped women and children in other ways, like jobs and housing, and how to maintain your health. I am very grateful for this experience, and I will continue to work with the YWCA to help other women to be able to get the same help that I got.

Senator, I want to thank God for you, too. You know, I watch you a lot when you don't know I'm watching you, on TV. You get the job done, and I thank God for that. I know God takes care, but he works through people, and I am grateful for that. And I am so grateful to the YWCA, I'll probably just ask them to help me find a job, because I won't be 60 until November, and I need some money today. So I might now just ask them to help me find a job.

[The prepared statement of Ms. Brown follows:]

PREPARED STATEMENT OF LILLIAN BROWN

My name is Lillian Brown. I am very honored to be her4e to day to tell you about how I learned about the importance of mammograms. Thank you Senator Mikulski and Senator Kennedy for making it possible for me to tell my story—I think it is the story that many other women should have too.

I live on North Caroline Street in Baltimore, MD. I have three foster children. My life is full and happy, and I have my health. However, until last October, at age 59, I had never had a mammogram. I had never really thought that breast cancer might affect me, or that I should be getting regular mammograms and breast examinations from my doctor.

Sure, I saw some television ads that talked about breast cancer, but I did not know exactly what I should do, how expensive they were, or where to go, and I felt bad about that.

All that changed last fall when the YWCA in Baltimore came to my neighborhood—to our churches and clinics—and invited me and other women to participate in a very special program. The YWCA reached out to me, and made all the arrangements. They spent time with me on the telephone and reassured me, because I was really afraid. The YWCA gave me transportation to Johns Hopkins Hospital where my group of 12 women had a wonderful class taught by a nurse.

We learned breast self exam and regular check ups. We learned all about mammograms from our teacher. We learned about how important early detection can be.

We watched interesting videos, and did role play where we learned how to talk to other women about getting a mammogram. We really had fun and were given a delicious lunch. We learned not to be afraid. And then we got our mammograms.

The community volunteers helped us in every way: To fill out forms, to go with us to the mammography room and to talk with us on the drive to and from the hospital. The YWCA women explained that if there was a problem with the mammogram they would be there to help us. And they did help some women in our group who needed to go back for more tests.

I won't forget this very special day. And I won't forget what I learned. And I will get regular mammograms, now that I understand what to do and where to go.

I now go back to the YWCA to help them teach new groups of women. I talk to my neighbors and my friends about getting mammograms. I tell them that mammograms don't hurt. They won't give you cancer. And they might just save your life.

I tell them to just call the YWCA. It is a safe place to go for help. I think the YWCA knows how to take care of women. They know that sometimes it is very complicated to figure out how to get what you need. And they help you do it.

I know that the YWCA has always helped women and children in other ways, like job training and housing. So maybe it is no surprise that they are now helping us to get mammograms. And to learn what we need to know to take care of ourselves.

I am very grateful for this experience and I will continue to work with my YWCA to help other women get this help, to get the message, and to get regular mammograms.

Senator MIKULSKI. Well, thank you very much, Ms. Brown, for that eloquent testimony. Now that you have done this wonderful commercial for both the dear Lord and the YWCA, we'll talk to the Lord later on today, but let's talk to the YWCA now.

Thank you very much, Ms. Brown.

Ms. Jackson, you are the vice president of the YWCA of the USA, based here in Washington. And of course, one of the hopes of the program was to be able to reach out to all groups of women, with particular focus on women of color, who are often left out and left behind.

Would you share with us your experiences with this program and your suggestions for it?

Ms. Jackson. Thank you very much, Senator Mikulski.

Just one correction. We are not based in Washington, DC, but our offices are in New York. I happen to live, actually, in Maryland, so you are my Senator.

And also to Senator Wellstone, thank you very much for inviting us here today.

My name is Alexine Clement Jackson, and as you said, I am first vice president of the YWCA. I think we have to learn to say it like you do—the Y-W-C-A of the U.S.A.

I am most honored to be here today to provide the committee with testimony about the YWCA's promising collaboration in the National Breast and Cervical Cancer Early Detection Program, Title XV, administered by the Federal Centers for Disease Control and Prevention, a collaboration that we believe holds tremendous promise for meeting the challenges in health care we now face in the United States.

Indeed, the subject of health care is now in the center of our Nation's mind's eye. The search for solutions is underway to the tough questions that begin with technical issues of cost and efficacy and extend to practical and ethical matters of equality of access and quality of life. Therefore, it is especially important to describe what may be a small but tremendously instructive example of what is possible for the common good as our Nation moves along the road to health care reform.

Executed in March of this year, the YWCA-CDC collaborative agreement provides for a unique partnership between the Federal Centers for Disease Control and Prevention and the oldest and largest women's membership movement in the United States and the world, the YWCA. The Title XV program goals and the YWCA mission are a perfect mirror image.

For 135 years, the YWCA has been committed to the empowerment of women and the elimination of racism. Each and every program effort of our membership movement is conceived and implemented through the prism of our mission.

The Title XV program is designed to bring education and services to medically underserved women, empowering those who have had limited or no access to the health care system to obtain critical cancer screening services and, in the process, to obtain knowledge about their own health care that will enable them to live healthier, more fulfilling lives.

The components of our collaborative agreement are designed, first, to reflect the reality that removal of the cost barrier alone will not be enough to reduce mortality from breast cancer, and then to provide the human resources and organizational expertise to State-sponsored screening programs that will open doors to quality health care for women of all socioeconomic groups.

As partners with CDC in education and early detection, the national board of the YWCA of the U.S.A. and its member associations will do the following: participate in national and local efforts to join our resources, personnel, and health promotion expertise with those of the CDC-funded State programs; provide outreach, recruitment and ancillary service that remove barriers to access health education and medical services to include transportation, day care, breast health seminars, and peer support; provide critical follow-up support for program participants who are diagnosed with breast cancer; and finally, collaborate in the development and evaluation of materials and collaborate in behavioral and intervention research.

In short, our 400 member associations will function as a much needed network of "navigators" at every level of the educational and service delivery process.

Our national board and staff will commit the full force of our resources to supporting the efforts of our member associations and by providing training, supervision and quality assurance of local programs.

The YWCA of the U.S.A. will implement our partnership with CDC through the expansion of our "ENCORE" program, an 18-year-old program of support, counseling and exercise for women with breast cancer. Our new program, which is renamed "ENCORE-Plus," will include outreach, public education and referral to screening services, as well as the treatment and posttreatment support program components that have been in place for many years.

Our ENCORE-Plus program provides a strong philosophical and programmatic framework for YWCA expansion into early detection.

The institutional relationships, experience and skills gained in building the ENCORE-Plus program and our partnership with CDC over the course of the next several years will create a strong infrastructure through which other women's health programs can

and will be delivered. In doing so, it will create a viable model and other opportunities for collaboration with CDC and other branches of the U.S. Public Health Service.

Our collaborative agreement with CDC originally was targeted for 13 States, yet the interest on the part of State health departments and our member associations has been so enthusiastic that we now have collaborative activity in 23 States.

As someone who grew up in the YWCA and has been a volunteer in the YWCA movement for most of my life, I know how much we have to contribute to women's health in this country. But I have also seen the needs of women and the problem of breast cancer from the other side, as a woman who was diagnosed and treated for breast cancer 7 years ago.

My love and belief in the power of the YWCA mission and capabilities is reaffirmed constantly and in many different ways, yet no more dramatically as I see us dedicate our vision and our resources to reducing mortality from breast and cervical cancer.

In sum, the YWCA-CDC partnership provides a clear answer to an important question: What is the YWCA really about? Simply put, it is whatever the girl or the woman needs next. The YWCA is here to meet today's challenge of breast and cervical cancer, and we will be there in the future to meet other challenges, continuing our legacy of commitment and actualizing our belief that physical well-being is essential to the empowerment of the whole person.

Thank you very much.

[The prepared statement of Ms. Jackson follows:]

PREPARED STATEMENT OF ALEXINE JACKSON

Thank you, Senator Mikulski, Senator Kennedy and members of the Committee on Labor and Human Resources for inviting me to testify today.

My name is Alexine Clement Jackson. I am the First Vice-President of the National Board of the YWCA of the U.S.A.

I am most honored to be here today to provide the committee with testimony about the YWCA's promising collaboration in the National Breast and Cervical Cancer Early Detection Program (Title XV) administered by the Federal Centers for Disease Prevention Control, one that we believe holds tremendous promise for meeting the challenges in health care we now face in the United States.

Indeed, the subject of health care is now in the center of our Nation's mind's eye.

The search for solutions to the tough questions that begin with technical issues of cost and efficacy, and extend to practical and ethical matters of equality of access and quality of life is underway.

Therefore, it is especially important to describe what may be a small but tremendously instructive example of what is possible, for the common good, as our nation moves along the road to health care reform.

Executed in March of this year, the YWCA-CDC Collaborative Agreement provides for a unique partnership between the Federal Centers for Disease Prevention and Control and the oldest and largest women's membership movement in the United States and the world, the YWCA.

The Title XV program goals and the YWCA mission are a perfect mirror image: For 135 years, the YWA has been committed to

—the empowerment of women, and

—the elimination of racism.

Each and every program effort of our membership movement is conceived and implemented through the prism of our mission.

The Title XV program is designed to bring education and services to medically underserved women, empowering those who have had limited or no access to the health care system to obtain critical cancer screening services and, in the process, to obtain knowledge about their own health care that will enable them to live healthier, more fulfilling lives.

The components of our Collaborative Agreement are designed:

—to reflect the reality that removal of the cost barrier alone will not be enough to reduce mortality from breast cancer and
—to provide the human resources and organizational expertise to State-sponsored screening programs that will open doors to quality health care for women of all socio-economic groups

As partners in education and early detection with CDC, the National Board of the RCA of the U.S.A. and its member associations will:

—participate in national and local efforts to join our resources, personnel and health promotion expertise with those of the CDC-funded State programs
—provide outreach, recruitment and ancillary services that remove barriers to access health education and medical services, including transportation, day care, breast health seminars and peer support
—provide critical follow-up support for program participants who are diagnosed with breast cancer
—collaborate in the development and evaluation of materials and the conduct of behavioral and interventions research.

In short, our 400 member associations will function as a much-needed network of "navigators" at every level of the educational and service delivery process.

Our National Board and staff will commit the full force of our resources to supporting the efforts of our member associations and by providing training, supervision and quality assurance of local programs.

The YWCA of the U.S.A. will implement our partnership with CDC through the expansion of the our ENCORE program—an 18 year-old support, counseling and exercise program for women with breast cancer.

Our new program, which is named ENCORE plus, will include outreach, public education and referral to screening services, as well as the treatment and post-treatment support program components that have been in place for many years.

Our ENCORE program provides a strong philosophical and programmatic framework for RCA expansion into early detection.

The institutional relationships, experience and skills gained in building the ENCORE plus program and our partnership with CDC over the course of the next several years will create a strong infrastructure through which other women's health programs can and will be delivered. In doing so, it will create a viable model and other opportunities for collaboration with CDC and other branches of the U.S. Public Health Service.

Our Collaborative Agreement with CDC originally targeted 13 States, yet the interest on the part of State health departments and our member Associations has been so enthusiastic that we now have collaborative activity in 23 States.

As someone who grew up in the YWCA and who has been a volunteer in the YWCA movement all my life, I know how much we have to contribute to women's health in this country, but I have also seen the needs of women and the problem of breast cancer from the other side, as a woman who was diagnosed and treated for breast cancer 7 years ago.

My love and belief in the power of the YWCA mission and capabilities is reaffirmed constantly and in many different ways, yet no more dramatically as I see us dedicate our vision and our resources to reducing mortality from breast and cervical cancer.

In sum, the YWCA-CDC Partnership provides a clear answer to an important question: "What is the RCA really all about?"

Simply put, it is whatever the girl, or the woman, needs next.

The YWCA is here to meet today's challenge of breast and cervical cancer.

We will be there in the future to meet others, continuing our legacy of commitment and actualizing our belief that physical well-being is essential to the wellness and empowerment of the whole person.

COLLABORATIVE AGREEMENT

Purpose—In March 1993, CDC entered into a collaborative agreement with the YWCA of the USA, to work together on national and State-based activities for the early detection of breast and cervical cancers. Linking women to available screening services and providing appropriate health education activities is critical to the success of the CDC National Breast and Cervical Cancer Early Detection Program.

Plans—The YWCA of the U.S.A. strives to create opportunities for women's growth, leadership and power in order to attain a common vision: peace, freedom and dignity for all people. Women's health is fundamental to the creation of these opportunities and the pursuit of the YWCA vision.

As partners in prevention and education, the CDC and the YWCA will initiate pilot activities in 13 of the 30 States currently funded by CDC: Arkansas, California,

Iowa, Maine, Maryland, Massachusetts, Minnesota, New York, Ohio, Pennsylvania, South Carolina, Texas, and Washington.

YWCA Associations will participate in national and local efforts to familiarize state health agencies with 1) their resources, programs, and expertise in health promotion, including the ENCORE Plus national breast health education, screening, and yearly reminder model program, 2) their capacity to provide ancillary services that remove barriers to access health education and medical services, including transportation, day care, counseling, education, and peer support, and 3) provide critical follow-up for women diagnosed with breast cancer.

CDC will encourage States to develop linkages and active collaborations with local YWCA Associations in the areas of service delivery and health education. YWCA representation on State breast and cervical cancer control coalitions is also encouraged.

CDC will provide technical assistance to the YWCA in the development and evaluation of new materials and the conduct of behavioral and interventions research.

This is an excellent model of interested organizations collectively working together to provide vital services to the women in their community.

HISTORY

The Young Women's Christian Association (YWCA of the U.S.A.) began its work in the United States in the mid-1850's. Today, there are community and student YWCA's in all 50 States

with national headquarters at 726 Broadway, New York, NY 10003. Other national offices are in Phoenix, AZ and Washington, D.C.

The YWCA of the U.S.A. is a member of the World YWCA which is at work in over 90 countries from headquarters in Geneva, Switzerland.

THE MISSION

The Young Women's Christian Association of the United States of America is a women's membership movement nourished by its roots in the Christian faith and sustained by the richness of many beliefs and values. Strengthened by diversity, the Association draws together members who strive to create opportunities for women's growth, leadership and power in order to attain a common vision: Peace, justice, freedom and dignity for all people.

The Association will thrust its collective power towards the elimination of racism wherever it exists and by any means necessary.

ORGANIZATIONAL STRUCTURE

The YWCA of the U.S.A. operates at three levels: 1) through the work of the National Board and staff to sustain the movement and build a strong nationwide network of member Associations; 2) through the work of 400 autonomous community and student YWCAs which provide direct services to over 2 million girls, women and their families at over 4,000 sites in all 50 States; 3) through the YWCA of the U.S.A.'s membership in the World YWCA.

YWCA facilities range from skyscrapers and community centers to neighborhood houses, campus centers, storefronts and mobile vans. Constantly in touch, 28 regional and State councils have been formed to network and keep YWCA leaders up-to-date as resource centers and links between members, Associations and the national office. YWCA's are also linked to through YWNET, the YWCA's own electronic network service for exchanging news, information, research findings, public policy alerts and much more.

PROGRAMS

The YWCA of the U.S.A. National Board and staff advance the Mission through Advocacy and Research, Development and Public Relations, and Member Association Services designed to strengthen and unite all YWCA's in a cohesive, mission-based movement. This includes the delivery of ongoing executive leadership training and staff development at national and regional training forums; fiscal oversight and standards/accreditation enforcement; networking and communications; public policy liaison and financial development services.

The YWCA of the U.S.A. also serves as a conduit through which national programs are strategically developed, refined and disseminated across the country. Women's Health Initiatives include ENCORE breast health education and screening outreach and ENCORE post-operative exercise and peer support for those who have had breast cancer surgery. YWCA SPORTS ADVOCACY include tennis, gymnastics,

field hockey, swimming, basketball, and aquatics management training for underserved inner-city girls and young women across the country.

TOMORROW'S WOMEN, a unique national partnership between the YWCA of the U.S.A. and Girls Incorporated, builds leadership, decision-making skills and self-esteem among girls, ages 6 to 18 years. The INSTITUTE FOR PUBLIC LEADERSHIP increases the vision, voice and impact of women politically by teaching the how-tos of running for office, managing campaigns and issues advocacy. EDUCATION FOR GLOBAL RESPONSIBILITY enables YWCA staff and volunteers to link their members' experiences in promoting social change at the grass-root community level with the development needs of women and girls worldwide.

SOCIAL ACTION/PUBLIC ISSUES

The YWCA has been a leader in social change throughout its history. Although Associations are free to work on those issues of greatest concern to their own members, advocacy for civil rights legislation and women's rights is an integral part of all social action and advocacy efforts.

The 1991 YWCA convention selected seven issues as predominant in the work of the 1991-94 cycle. Stress is on these five national public priorities: Equity, Economic Security, Housing and Homelessness, Child Care and Family Leave, Health and Reproductive Choice. The two central YWCA international priorities are a United States foreign policy committed to Peace and Sustainable Development and based on support of Human Rights and Accountability to the People.

FUNDING

Member YWCA's are funded through United Way allocations, membership dues, individual contributions and program fees. The YWCA of the U.S.A., National Board is funded by support from member Associations, contributions from individuals, corporations and foundations, income from endowment and from its own services.

THE YWCA OF THE U.S.A.

The YWCA of the U.S.A. is the oldest and largest women's membership organization in the United States. For 135 years the organization has devoted itself to developing programs that further its mission: the empowerment of women and the elimination of racism. Through educational, sports, health, skill development, social service and leadership training programs offered by its 400 member Associations, the YWCA of the U.S.A. serves millions of women and girls of diverse backgrounds.

The YWCA of the U.S.A. has a long-standing commitment to women with breast cancer and the unique ability to bring quality breast health education, screening and support services to thousands of women in need of such services throughout the United States through our extensive nationwide network of member Associations.

THE HISTORY OF ENCORE

ENCORE is a highly respected, national program for women who have undergone surgery and treatment for breast cancer. Under the direction of a YWCA certified specialist, ENCORE offers 1) individually tailored exercises (pool and floor) to help women recover from surgery and maintain a positive self-image; 2) information and guidance concerning treatment and recovery issues from community-based medical specialists, and 3) informal peer-support groups. ENCORE is ongoing, so women may enter it directly after surgery and other treatment for breast cancer and return to it, over a period of many years, if necessary.

The program was developed in 1972, pilot tested for four years, and adopted as a National Board program in 1976. Throughout its history, ENCORE has empowered women with breast cancer to manage their physical and emotional health and make decisions concerning treatment options. YWCA's offer ENCORE programs in a variety of geographic, socioeconomic and ethnic settings. Each site has developed local support networks, adapting ENCORE to fit its situations and the needs of its communities.

ENCORE creates a supportive, caring, non-judgmental atmosphere so participants can safely share their concerns, evaluate information about; treatment and recovery, and learn ways to develop and maintain their own strength, health and psychological well-being.

ENCORE is currently offered at 150 local YWCA Associations across the United States. It provides trained personnel and an environment where breast health and screening may also be offered to asymptomatic women who have reached the age when regular clinical breast exam and mammography screening is appropriate.

Until scientific research yields effective modes of prevention and ultimately a cure, early detection is key to reducing mortality from breast and cervical cancer. These diseases are serious health problems for the women of this country. The YWCA of the U.S.A. believes that health is fundamental to every aspect of a woman's well-being and potential; thus, early detection programs are a top priority of the organization. To fulfill this goal, the YWCA will expand the ENCORE program to include breast health education and screening.

THE "PLUS" IN ENCORE PLUS

—The 1991-1992 Pilot Effort

Simply being a woman puts every woman at risk for breast and cervical cancer, ad that risk increases with age. 182,000 women will be diagnosed with breast cancer and approximately 13,500 with invasive cervical cancer in 1993. Although incidence rates for white and minority women are similar, mortality rates for minority and low-income women are high due to lack of access to education, screening and treatment services. The YWCA of the U.S.A. and its member Associations are responding to this public health challenge by developing ad implementing a comprehensive education, screening and support program—ENCORE plus.

During the past few years, many member YWCA Associations have tested various approaches to breast health and mammography screening programs for age-eligible, low-income and uninsured women. The pilots targeted women over 50 and were designed to remove known barriers to access (cost, lack of awareness of need, transportation, lack of a referring physician) and to enable participants to understand what they need to do to protect their health. The YWCA of the U.S.A. has developed a positive working relationship with the U.S. Public Health Service, including technical assistance and materials development, in the pilot effort.

The basic features of the ENCORE plus program that were tested and evaluated in the pilots include:

—Preliminary medical history and clinical breast exam
—Transportation to and from program site
—A combined education and mammography screening experience in a supportive, informal, peer group setting.
—A one-hour seminar that incorporates innovative video materials and instruction in breast self-exam taught by a trained health professional, followed by a screening mammogram.
—Lunch and day care, if necessary.
—Printed educational materials to take home
—Patient follow-up in cooperation with service providers so that participants receive the care they need.
—Program evaluation and changes and improvements as appropriate.
—Referral to ENCORE or other support pup for any worn: diagnosed with breast cancer.
—Annual reminders to participants with instructions as to available low or no-cost mammography screening services.

Results of the 1991-1992 pilot effort reflect significant increases in breast health knowledge. The positive, supportive approach and the ancillary services, particularly transportation, had a dramatic effect on participant's attitudes about their participation in the program and to the screening experience itself. An extremely high proportion of the women expressed their intention to follow regular screening guidelines. The pilots provide a solid base of experience from which the YWCA of the U.S.A. will move forward to promote its national ENCORE plus program.

The ENCORE plus program is intended to be flexible and dynamic, so that it may be adapted and intepted into other local breast cancer education, screening and treatment programs in cooperation with State health departments and private medical providers. Centralization of ENCORE plus program development, training and administration by the YWCA national staff will assure the quality of evaluation ad future program implementation.

—Future Implementation: A Partnership with CDC

The YWCA of the U.S.A. has finalized a Collaborative Agreement with the Federal Centers for Disease Control and Prevention's (CDC) Breast and Cervical Cancer Screening Program. This important Federal initiative provides the framework to bring both quality screening and education to medically underserved women in numbers never before possible. To succeed, it will require the support of physicians, other medical providers and community-based organizations who know how to meet the needs of the targeted populations.

The YWCA's unique and historic mission of service to women and our infrastructure of facilities and experienced, caring professional and volunteer resources en-

ables it to serve as a strong partner with which the CDC, State health departments and service providers may collaborate to accomplish the long-term goals of the program.

The YWCA-CDC partnership will:

—include YWCA representatives in coalitions and planning efforts sponsored by CDC-funded States;

—target 12 States during the first year (April 1993-April 1994) that have either comprehensive or core planning funding from CDC: Maryland, New York, South Carolina, Texas, Minnesota, Ohio, Pennsylvania, Maine, Arkansas, California, Massachusetts, and Washington;

—foster linkages and active collaborative relationships between State health departments and YWCA Associations in the areas of service delivery and health education;

—sponsor joint education and training sessions

The YWCA of the U.S.A. will secure private support, as well as available public funding, for this implementation of the ENCORE plus program and the partnership with CDC.

Senator MIKULSKI. Thank you very much, Ms. Jackson.

Now, we'll turn to Ms. Vicky Rakowski, representing the American Cancer society. Ms. Rakowski is a registered nurse—and, Ms. Rakowski, what does the "ET" stand for?

Ms. RAKOWSKI. It stands for "enterestimal therapist." I have a specialty in dealing with G.I. and oncology patients.

Senator MIKULSKI. I see. Please go ahead with your testimony, which we eagerly anticipate.

Ms. RAKOWSKI. Thank you. Good morning, and thank you for the opportunity to be here also.

Senator MIKULSKI. And by the way, if you don't want to read at all, you can summarize it, and we'll make sure the entire statement is included in the record.

Ms. RAKOWSKI. Thank you.

I want to say that in addition to my written statement, I have also included a written statement from our South Carolina division.

Senator Mikulski, the American Cancer Society has been a strong supporter of this program right from its inception. In fact, in Michigan, we helped write for the grant that we received as one of the first eight States. This program is an outstanding example of a significant public-private sector partnership that meets critical health needs for women across the Nation.

Following the passage of Title XV, the American Cancer Society and the CDC signed a collaborative agreement to ensure that the program reached its potential in the community. The American Cancer Society accepts no government funding, but we have committed resources from the moneys we raise privately to support the Title XV program in Michigan and in other States.

Under the agreement with the CDC, the American Cancer Society will work with the agency and State and local health departments in developing and distributing educational materials, conducting training for States to participate in the program, and in forging community-based partnerships to reach underserved women.

In Michigan and in many other States, we have been very successful because of these strong partnerships. The Federal dollars act as seed money for local agencies and organizations to take on the responsibility of educating and recruiting women to participate in their early health care screening and provide a community-based

network for treating women who are diagnosed through the program.

The American Cancer Society provides a grassroots presence in every Title XV community in our State, which enables us to educate women about the need for early screening and get information about the program out to the at-risk populations. And currently, out of the 82 counties in our State, over 60 are currently involved very strongly in the program.

In Michigan, since July 1991, the American Cancer Society has supported this program with over $4.2 million of direct and in-kind donations.

Senator MIKULSKI. Excuse me. In addition to the Federal dollars, the American Cancer Society has value-added $4.2 million in direct and in-kind?

Ms. RAKOWSKI. That's correct.

Senator MIKULSKI. I wanted to be sure I understood that and that it is in the record.

Ms. RAKOWSKI. That is correct.

Many other agencies have been involved with us as partners in this as well, at local community-based. One of the important components of our program is that all of our project is delivered through local public health departments in the State of Michigan, and in order for them to have this contract given to them, they have to be partners with the American Cancer Society, and within that two-agency initiative, create a community-based partnership of a local coalition to develop the infrastructure and programs that are necessary for the women.

Over 8,000 women have been screened to date in Michigan. Of those, 55 percent have been at the poverty level, and over 60 percent have been uninsured. Out of those women who have been screened, 33 breast cancers have been found, and within the age categories that we track, interestingly enough, 11 of those cancers were found in situ, meaning at its very earliest stage. Between 40 and 49 years of age, there were seven found. Between 60 and 64 years of age, there was one, and over 65 years of age, there were three breast cancers found in situ.

Invasive breast cancers found were 20, and between the ages of 40 and 49, there were eight of them; from 50 to 64, there were eight women who had invasive, and over 65, there were four.

I think that is significant in looking at the importance of continuing the screening from the age of 40 and above.

We have found 12 cervical cancers—six at the earliest stage and six at an invasive stage. Again, it has proven to be that the largest number of those were screened in the 40 to 49 year age bracket.

This program also provides an opportunity for education of women in screening behaviors. Of all of the total women screened in Michigan, 43 percent were under the age of 50. These women now know they need to include regular screening mammography and Pap tests in their health plan. They are aware of the risk factors for breast and cervical cancers and are more likely to continue to seek screening services in the future.

The American Cancer Society strongly supports reauthorization of this program. However, there are some policy changes which we believe would greatly benefit the program. First, prior to this year,

States were permitted to count donated diagnostic and treatment dollars as part of the State match as required under the program. However, under a new interpretation by the Centers for Disease Control, States are no longer permitted to count these services. This makes the application process for new States or States wishing to expand their programs very difficult. I would urge you to consider clarifying the statute to allow contributions of diagnostic and treatment services count.

The provision prohibiting State health departments from contracting with private sector mammography facilities also has a negative impact on the program's success. Not only does this limit women's access, but it causes problems with private facilities and private practice physicians, ob-gyns, who wish to participate in the program. It also undermines the community health infrastructure.

An important requirement of the statute has been the strong commitment to ensure the quality of the screening procedures provided under the program. After the Mammography Quality Standards Act of 1992, or MQSA, goes into effect, we believe that quality standards for mammography services provided under Title XV should be amended to be consistent with MQSA, thus assuring high quality and avoiding duplicative, unnecessary regulation.

Senator Mikulski, the American Cancer Society applauds your continuing efforts to achieve high-quality standards for all cancer screening programs.

Finally, we are concerned about the construct of this program which impacts on our ability to reduce mortality from breast and cervical cancers. Under the law, Federal funds may not be used to pay for diagnostic and treatment services determined by the screening process to be needed by indigent, uninsured women. In fact, it depends on the good will of the private sector to meet these critical service needs.

A dependable treatment component is essential to the long-term success of any screening program. While in most communities, this need is met voluntarily by the private sector, and we understand that all women who have needed services so far have been referred for appropriate follow-up care, this restriction on the use of funds represents a significant barrier to participation for some communities. We have certainly felt that in Michigan in many of our rural, very small hospital kind of counties. This is a tremendously important program with a proven track record of success in reaching women who are at risk of dying of breast and cervical cancer. To reach women nationwide, we recommend as the American Cancer Society that you provide authorization for full funding in fiscal year 1994 an beyond, at a minimum level of $200 million—the amount which will enable CDC to implement a comprehensive program in every State and to enable States with existing programs to make services available statewide.

Thank you very much.

[The prepared statement of Ms. Rakowski follows:]

PREPARED STATEMENT OF VICKI RAKOWSKI

Good morning. I am Vicki Rakowski, RN, ET, vice president for cancer control, American Cancer Society, Michigan Division. I would like to thank you for the opportunity to be here this morning. I will briefly discuss the importance of breast and cervical cancer screening, and reauthorization of the first comprehensive program

for breast and cervical cancer control which combines outreach and education with medical screening and counseling.

The American Cancer Society is the nationwide voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer, and diminishing suffering from cancer through research, education and service. Senator Mikulski, the American Cancer Society has been a strong supporter of the Title XV program, which you sponsored, from its inception. This program is an outstanding example of a significant public/private sector partnership that meets critical health needs for women in Michigan and across the country.

Breast cancer will effect 6,800 women in Michigan, and over I 80,000 women nationwide this year alone. Treatment of this disease represents a significant burden on our nation's health care system. If breast cancer is not diagnosed until it has spread with distant metastases, the 5-year survival rate is 18 percent, and the treatment modality is extensive and extremely costly. Detecting breast cancer in an early stage through mammography results in a 93 percent 5-year survival rate, with much less extensive treatment and more choices for the woman. In fact, the American Cancer Society estimates that 27,300 women's lives could be saved from breast cancer each year if these women had access to early detection and appropriate treatment. These women can remain active and productive members of our economy, and will not drain our Nation's health care resources.

Similarly, cervical cancer will effect 13,500 women and cause 4,400 deaths in this country this year. These represent completely unnecessary deaths; the Pap test is highly effective in the early detection of cervical cancer. Over the past 70 years, the mortality rate from cervical cancer has decreased by more than 70 percent, due largely to use of the Pap test.

The tragedy, Madame Chairman, is that these life-saving procedures are not accessible to all Americans, and too many people are dying and suffering needlessly. This is because our health care system focuses on treating illness rather than preventing or detecting it at an early stage. The Title XV program has made a significant step in changing this.

Given the medical value of breast and cervical cancer screening exams, one would assume that the procedures would be widely used. Unfortunately, this is not the case. Compliance with health prevention/screening guidelines is a particular problem for socioeconomically disadvantaged Americans. The high cost of medical procedures, particularly with regard to mammography, presents a strong barrier to the use of screening. Because of poor access to screening procedures, the poor are more likely to be diagnosed with cancer when the disease is more advanced and the treatment options are significantly more limited.

Mortality rates for both breast and cervical cancer today are highest among women of lower socioeconomic status. While this problem is due in part to a low awareness of the warning signs of cancer, and to lack of funds to pay for care, the incidence of late diagnosis among the poor is also a reflection of inadequacies in the health care system. According to testimony from regional hearings the American Cancer Society conducted in 1989, it is a system which discourages preventive health care and routine screenings, and which encourages patients to wait until their health problems are virtually unbearable before seeking care, and which imposes unnecessary delays in diagnosis.

If the use of appropriate cancer screening is to become more widespread, educational efforts must be intensified and the procedure made more accessible through low-cost, high quality screening centers such as established under the Title XV program. In addition, because women of low socioeconomic status—white, African-American, Hispanic, and other ethnic groups—are the least likely to know about the benefits of mammography and Pap tests or to be able to afford the procedures, health program planners and practitioners should focus on service delivery to this group. The Title XV program facilitates this targeted screening.

The Centers for Disease Control and Prevention (CDC) and the American Cancer Society have identified the control of breast and cervical cancer as critical priorities. In fact, the American Cancer Society played an active role in the development of recently released National Strategic Plan for the Early Detection and Control of Breast and Cervical Cancer. In addition, following passage of the Breast and Cervical Cancer Mortality Prevention Act (Title XV), CDC and the American Cancer Society signed a Collaborative Agreement to support national and State-based efforts in breast and cervical cancer control. This agreement supports the intent of the community-based screening grants under Title XV in establishing cooperative partnerships between CDC, State health departments and nonprofit organizations such as the American Cancer Society. Specifically, CDC and the American Cancer Society have agreed to work together in developing and distributing educational and media

materials on breast and cervical cancer and to discourage duplication of efforts and conserve limited resources through joint pre-testing and development of new materials. The American Cancer Society joined with CDC and other groups in developing and conducting training for individuals in states which received a Title XV grant. This training covered all aspects of breast and cervical cancer screening, education and outreach to special populations. The American Cancer Society was able to share what it has learned in over 80 years of direct services to the community. Finally, an important component of the Agreement has been to encourage state health departments and American Cancer Society to work together to implement the breast and cervical cancer control program, by identifying interrelated and supportive roles and responsibilities in each State. This Agreement has provided an outstanding opportunity for the American Cancer Society to work in conjunction with the Federal Government, State and local public health departments, and other organizations, to provide much needed services directly to women. A copy of the Agreement is attached to my written statement.

In Michigan and in many other States, we have been very successful because of the strong partnerships this program has fostered between government and the private sector. The Federal dollars act as seed money as local agencies and organizations take on the responsibility of educating and recruiting women to participate in early health care screening, and providing a community-based network for treating women who are diagnosed through the program.

The American Cancer Society provides a grassroots presence in every Title community in our State, which enables us to educate women about the need for early screening and get information about the program out to at risk populations. In Michigan, since July 1991, we have supported this program with over $4.2 million in direct and in-kind donations. Many other agencies have been involved in these communities as well. Since one of the top three most often cited reasons women do not obtain a screening mammogram is cost, this program enables us to leap that barrier and provide screening to underinsured and uninsured women. Of the over 8,000 women who have participated in the program in Michigan, over 55 percent have been at poverty level, and over 60 percent have been uninsured. This program offers the only hope these women have of accessing screening services and appropriate followup care.

This program gets women into a screening program, which offers not only direct services, but educates them about their long-term screening and health needs. Of the women screened in Michigan, 43 percent were under the age of 50. These women now know they need to include regular screening mammography and Pap tests in their health plan, they are aware of the risk factors for breast and cervical cancer, and they are more likely to continue to seek screening services in the future.

As I have indicated, the American Cancer Society strongly supports reauthorization of the Title XV program. However, there are some policy changes which, based on our experience in Michigan, would greatly benefit this program. First of all, in order to apply for funds, State health departments must provide matching funds on a 1:3 basis, either with hard or in-kind contributions. Prior to this year, States were permitted to count donated diagnostic and treatment dollars as part of the State match. However, under a new interpretation by CDC, States can no longer count donated diagnostic or treatment funds. This makes the application process for new States, or States wishing to expand their program, very difficult, since they must still provide diagnostic and treatment services, but can no longer count them as part of the match. I would urge you to consider amending the statute to allow these contributions to count.

Another provision prohibiting State health departments from contracting with private-sector mammography facilities also has a negative impact on the program's success. It represents a problem with private facilities and private practice OB-GYN's who wish to participate; it limits access, and in turn, undermines the community health infrastructure.

An important requirement of the statute has been the strong commitment to assure the quality of the screening procedures provided under the program. The American Cancer Society believes that the program should be amended to require mammography services provided under Title XV to comply with the standards that will become effective under the Mammography Quality Standards Act of 1992 (MQSA). The intent of MQSA was to establish one uniform, national standard for all facilities performing mammography, thereby assuring high quality and avoiding duplicative, unnecessary regulation. We do not believe that State inspectors should have to comply with one standard under MQSA, another for CDC of Medicare, and another for an existing State law. Senator Mikulski, the American Cancer Society applauds your continuing efforts, and those of other Members of this committee, to achieve high quality standards for all cancer screening programs.

Finally, I raise an issue of concern which, while not limited to the Title XV program, does impact on our ability to reduce mortality from breast and cervical cancers. Under the law, Federal funds may not be used to pay for diagnostic and treatment services determined by the screening process to be needed by indigent, uninsured enrollees. It in fact requires States to depend upon the "good will" contributions of the private sector to meet these critical service needs. A dependable treatment component is essential to the success of any screening program. While in most communities, this need is met voluntarily by the private sector, this restriction on the use of funds represents a significant barrier to participation for some communities. We are concerned that the long-term approach in this program must examine the issue of payment for services rendered on the front line—that is, reimbursement for screening—without similar resources being made available for critical diagnostic and treatment needs of women in the program.

This is a tremendously important program with a proven track record of success. Importantly, Title XV has enabled the Federal Government, in partnership with the States and private sector organizations, to build a public health infrastructure which addresses the critical health needs of women who are at risk of dying of breast and cervical cancer. To reach women nationwide, the American Cancer Society recommends that you provide authorization for full funding in fiscal year 1994 and beyond, at a minimum level of $200 million—the amount which will enable CDC to implement a comprehensive program in every state, and to enable States with existing programs to make services available statewide. Thank you for your consideration.

Collaborative Agreement Between the Centers for Disease Control and Prevention and the American Cancer Society

I. BACKGROUND

An estimated 1,132,000 Americans will be diagnosed with cancer in 1992 and an estimated 520,000 Americans will die. One of every five deaths in the United States is from cancer.

The key to reducing illness and death from many cancers is early detection, and timely follow up and treatment. Routine screening can detect many cancers at early stages when more treatment options are available and survival is improved.

For cancer of the breast and cervix, proven screening technologies, mammography and Pap smears, exist that have been shown to have a significant impact upon mortality. Essentially all of the estimated 4,400 deaths from cervical cancer are preventable if all women were routinely screened. Studies estimate that mortality from breast cancer could be reduced by as much as 30 percent with routine screening.

The Centers for Disease Control and Prevention (CDC) and the American Cancer Society (ACS) through activities at the national and State levels have identified the control of breast and cervical cancer as critical priorities. This agreement outlines activities that support State-based early detection and control programs directed by the CDC with resources for the "Breast and Cervical Cancer Mortality Prevention Act of 1990," and ACS 1breast and cervical cancer control activities. No fiscal resources are exchanged by the two organizations to support activities identified in this agreement.

II. PURPOSE

As partners in prevention the Centers for Disease Control and Prevention (CDC) and the American Cancer Society (ACS) enter into this collaborative agreement to support national and State-based efforts for the early detection of cancers of the breast and cervix. Activities outlined in this agreement support the CDC mission, "prevention of unnecessary disease, disability, and premature death" and the ACS mission, dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer, and diminishing suffering from cancer through research, education, and service.

III. RESPONSIBILITIES

CDC Responsibilities:

1. State programs funded by CDC will be eyed to develop a strong working relationship with their respective ACS Division, including ACS staff and volunteer representation on advisory and planning committees.

2 CDC will encourage the use of existing ACS education and media materials and discourage the development of new materials. This will serve to avoid duplication of efforts and conserve limited resources.

3. If new materials are needed, joint pre-testing and development will be encouraged and the ACS 1-800 number will be listed.
4. National ACS will participate with CDC and other appropriate organizations to develop Interim outcome measures for breast and cervical cancer control.
5. CDC will develop and conduct joint training efforts.
6. CDC will allow cost recovery for training of volunteers and for materials at the State and local levels.
7. National ACS and CDC will encourage State health departments and ACS Divisions to develop memoranda of understanding that identify interrelated and supportive roles and responsibilities.

CDC designates the following individual as the official point of contact for this Collaborative Agreement:

Centers for Disease Control and Prevention
Name: Jeffrey P. Koplan, MD, MPH
Title: Director, National Center for Chronic Disease
Prevention and Health Promotion
Address: 4770 Buford Highway, N.E. (K40) Atlanta, GA 30341-3724
Telephone: (404) 488-5401

III. RESPONSIBILITIES

ACS Responsibilities
1. ACS Divisions will be expected to develop strong working relationships with State health departments and include staff on ACS committees, where appropriate.
2 Neal ACS will develop programs/materials on breast and cervical cancer.
3. If new materials are needed, joint pre-testing and development will be encouraged and the ACS 1-800 -number will be listed.
4. National ACS will participate with CDC and other appropriate organizations to develop interim outcome measures for breast and cervical cancer control.
5. National ACS will develop and conduct joint training efforts.
6. National ACS and CDC will encourage State health departments and ACS Divisions to develop memoranda of understanding that identify interrelated and supportive roles and responsibilities.
7. National ACS will serve as a clearinghouse for information, materials, and training curricula relative to collaborative programs between Divisions and CDC-funded State health departments, to ensure all Divisions benefit from these experiences.
8. National ACS will promote public policy advocacy that supports the enhancement of collaborative breast and cervical cancer control efforts.
9. National ACS will provide access to information dealing with breast and cervical cancer interventions and materials through Community Health Information Database (CHID), and other means as needed.

ACS designates the following individuals as the official point of contact for this Collaborative Agreement:

American Cancer Society, Inc.
Name: Robert Smith, PhD
Title: Senior Director of Detection
Address: American Cancer Society, Inc. 1599 Clifton Road, N.E., Atlanta, GA 30329
Telephone: (404) 329-7610
Name: Nancy Lins
Title: Vice President, Public Education
Address: American Cancer Society, Inc. 1599 Clifton Road, N.E., Atlanta, GA 30339
Telephone: (404) 329-7611

IV. IMPLEMENTATION OF COLLABORATIVE AGREEMENT

The implementation of this Collaborative Agreement will be guided by the Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, and the American Cancer Society.

V. RESOURCES

No financial resources will be exchanged between CDC and ACS to conduct activities outlined in this Agreement.

VI. DURATION OF AGREEMENT

This Collaborative Agreement is effective when signed by both parties and shall remain in effect for a period of 5 years from the date signed. The Agreement may be renewed annually thereafter by written mutual agreement. The intent is to continue this mutually beneficial relationship long-term.

VII. MODIFICATION OR CANCELLATION

This Agreement may be revised by signature approval of both parties.
Cancellation of the Agreement may be accomplished only at the expiration of 90-day advance notification by either party.

AMERICAN CANCER SOCIETY

By: John R. Seffrin, PhD
Executive Vice President & Chief Staff Officer

CENTERS FOR DISEASE CONTROL AND PREVENTION

By: William L. Roper, MD, MPH
Director

POSITION STATEMENT OF SOUTH CAROLINA DIVISION FOR CDC PROGRAM

Presented by: John Ureda, Dr. P.H., Division Chairman Project Advisory Group, H. Christopher Wren, Division Executive Vice President, and Mary Ellen Gunter, Division Senior Vice President Cancer Control.

The South Carolina Division of the American Cancer Society has been involved with the South Carolina Department of Health and Environmental Control in the CDC Breast and Cervical Cancer Screening Project during the past two years. This cooperative project is just one of many partnerships which have been formed over the years between these two agencies.

When the American Cancer Society was initially approached by DHEC with the concept of a joint partnership for breast and cervical cancer screening and education, it made sense to link these two agencies together as both agencies have a presence in the local communities of South Carolina. More importantly, the American Cancer Society had a Public Education delivery system statewide through its volunteer network and would be the only agency in South Carolina that with some adjustments to current programs could serve the target populations which needed to be reached by this project.

It was felt by both the State Health Department (DHEC) and the American Cancer Society that the success of this screening and education project would lie in a systematic grassroots approach which would enable behavioral modification or change in these target communities. At the same time the "buy in" by these communities and populations that this change could bring about results that would be long lasting and effective was felt to be an additional benefit.

As a result of the initial ground work and preparation that was negotiated by both agencies, this past year has seen that over 165,00 women in the target populations, over the age of 40 years and in the 250 percent of poverty level and below have received an educational message on the necessity of breast and cervical cancer screening through personal contact from staff and volunteers working with the project.

Additionally, through the efforts of Mass Media communications, 765,000 women have been reached in the target population groups. Mass Media consisted of both print and visual campaigns.

The project also trained 470 community volunteers to deliver the breast and cervical cancer educational services of the program, (Best Chance Network). In many instances these volunteers have come from the target groups where the changes need to be effected.

An added bonus of this partnership has been an expansion of the South Carolina Division's capacity to reach and inform all women in need of screening. Overall in South Carolina this past year, we have been able to have over 386,000 contacts with women over the age of 40 years regarding breast and cervical cancer education and 1,870,000 mass media contacts have exposed women to this important message.

The program has been further expanded by the creation of Regional Task Forces comprised of a mixture of participants from the target populations, their gatekeepers, American Cancer Society staff and volunteers as well as Department of Health staff and project staff. These Task Forces have been instrumental in developing Local ownership of the Best Chance Network program through this grassroots

approach to education which has allowed the American Cancer Society to redirect its educational efforts into this segment of our population and ensure that those persons most in need of our educational messages have the opportunity to receive them.

It is therefore our opinion, that this project should be fully funded for a fourth year. We further strongly recommend that it be continued indefinitely to maintain and further the productive efforts already underway, or at least until such time that there is documentation of a distinct improvement in the statistics as they relate to the diagnosis, staging and overall survival rates among not only the target populations in South Carolina but among South Carolina women in general. Early detection and treatment of breast and cervical cancer is one of the best ways to prevent death from cancer.

Senator MIKULSKI. Thank you, Ms. Rakowski. I am going to ask you some questions, and then go to Ms. Jackson, and then wrap up with Ms. Brown.

First, in your testimony on page 4, you say one of the top three often-cited reasons why women don't obtain a mammogram is cost. Could you share with us what does that mean around the costs and the prohibitions, and also what were the other two reasons why women don't get mammogram screening?

Ms. RAKOWSKI. Cost is an extreme component in our State in particular with rural women who have no insurance or are underinsured, and so thus avoid making the choice to go and get that mammogram because they don't see it necessarily as a necessity yet in their lives; they don't have any problems, they don't feel sick, so why should they have this done.

Lots of women in our State have sort of seen it in the same way as going to the dentist. We don't make that kind of preventive health care choice when those dollars are needed for things like buying food for our children. So cost is a significant factor.

Another significant factor is not having it recommended by their health care provider. Dr. Wyatt talked earlier about Rhode Island, and we have done studies in Michigan, asking why did you get your mammogram, or why didn't you come before for your mammogram, and the reply is: "Because my doctor never told me to do that." Even for those who are seen by a regular physician and who do have insurance that adequately covers it, that same barrier seems to occur.

Probably the third largest barrier in our State is transportation for rural women in particular and urban women who cannot get to the centers and areas where they need to go.

Senator MIKULSKI. So, then, the three reasons are cost; the fact that there has neither been information from a private physician or significant saturation from public information to go; and then the barrier of transportation, which has been an issue for rural communities in particular from what I saw in Maryland.

I want to ask the question about public information, because that will be one of the issues I will probe more deeply with Ms. Jackson. People have suggested that maybe we need public service announcements on TV; or suppose everyone on a soap opera went to get a mammogram and talked about how important it is; or Oprah could do a couple of shows on it—and so on—all of which I am not minimizing. I think it would be great if all of the soaps had all women of all ages, instead of some of the things they do on television, going to get a mammogram. And maybe we need to show what it means to get a mammogram on television.

But isn't the question where do I go and how do I get it? And that's the next question. It is not only you should, but then, how. Isn't this one of the issues in whatever is the next step?

Ms. RAKOWSKI. Absolutely. We were fortunate in being able to do a sort of screening barrier survey and a research study with a couple of researchers at Michigan State University, particularly in rural women. And you can do all the public service announcements you want, but it is just sort of there.

When we looked at actually reaching those women and getting them involved in the program, the single most important factor was women encouraging other women, or their physician telling them to do it, and then taking away the barrier of cost, and then taking away the barrier of transportation, which the American Cancer Society has been integral in doing. If that is done, those women will come for their mammogram.

One of the interesting stories I can tell you from a rural area in Michigan up in the "thumb," actually my home town, Bad Axe, MI, has had a very good track record for getting women to come from three surrounding counties that were involved in the program. They all had facilities where these women could go, but they were all going to Bad Axe, and no one could figure out why they wanted to go to Bad Axe as opposed to Caro or Sanilac, since they were driving a long distance or getting driven a long distance to get there.

Senator MIKULSKI. I don't understand.

Ms. RAKOWSKI. These are towns in these counties. The reason they cited to go there was because their friend went with them; they were reached through a friend or family network; and there was a Walmart store. That was the other reason.

Senator MIKULSKI. It all sounds good to me. [Laughter.]

Ms. RAKOWSKI. So those are the barriers that we are pushing to overcome, and those seem to be cropping up consistently, no matter how much media hype we have done. We have just finished a huge campaign, but that in itself didn't make the big difference. It was one-on-one, women reaching other women, and physicians recommending.

Senator MIKULSKI. I want to come back to some of the technical aspects of the program, but first, let's go to Ms. Brown. Did you agree with what Ms. Rakowski just said, Ms. Brown, that it was the money, but it was also knowing where to go and being able to go with other women?

Ms. BROWN. Yes, I really do agree with her. When I went to get my mammogram, I went through the YWCA, and they picked me up. But my doctor also insisted that I get one, and my point to her was that I didn't have the money. But I was also afraid.

Senator MIKULSKI. What were you afraid of?

Ms. BROWN. Listening to other people say that it would hurt, and that if you don't have cancer, they squeeze your breast so hard, you could get cancer—which you can't listen to, because everyone is an individual. What might hurt Ms. Jackson might not hurt me, because we are all individuals.

And then, I had 12 other ladies along with Ms. Behsudi and Dr. Harder to walk through it with me. And a lot of the ladies had had a mammogram, and on the way, we talked about it on the bus. You

see, the YWCA makes transportation, but transportation wouldn't have been the issue for me, because I live within walking distance of Johns Hopkins Oncology. As a matter of fact, it is on Caroline Street, so transportation would not have been an issue for me.

Senator MIKULSKI. Well, let me come back to the fear. Were you afraid of the test and that it would be painful, or were you also afraid of hearing the results?

Ms. BROWN. I was afraid of both. But I was more afraid of it hurting me than I was of the results.

Senator MIKULSKI. I was, too, the first time I had a mammogram.

Ms. BROWN. And then when I got the results, they thought they saw something, and I had it done a second time, no problem. And then when they got that test back, everything was fine.

Senator MIKULSKI. Amen.

Ms. BROWN. And I am scheduled for another one soon, because once they think they see something, they want it done every 6 months. So at the end of this month, I'll go and get another one. I'll just walk there and go on in.

Senator MIKULSKI. But when you go back for your follow-up, Ms. Brown, you don't need to go with the 12 women; you'll go on your own.

Ms. BROWN. No, no. They walked through it with me, and all the fear is gone now. I'll just go.

Senator MIKULSKI. But for your initial experience with this, you wanted to be with your pals. Now, with these 12 women that you walked through in this group, why was that important to you?

Ms. BROWN. It seemed like it took away some of the fear, because some of them had been through it. And one lady said, "Oh, it's nothing," and one lady said, "My breasts are very small; they are much smaller than yours, and it didn't pinch me." And inside, I still had a little fear. But when I got in there, the lady who did the breast examination was very gentle, and she talked the whole time. So she walked through it with me, too, once I got back there to get the x-ray.

Senator MIKULSKI. So it was the management of the fear.

Ms. BROWN. Yes.

Senator MIKULSKI. And then being with others who talked with you and said it's OK—or, even if it does pinch here or there, it doesn't matter—I mean, my gosh, look at these damned earrings and shoes we women wear. You talk about things pinching. [Laughter.]

Ms. BROWN. That's right. My concern is my health. And then the main thing was how I was really convinced, after I said, no, I'm not going to get it done, was when I talked with Ms. Behsudi over the phone, the first phone call she made to me. I was in the process of going on a gospel tour, traveling down South, stopping in different places to sing with the church. I said, "I'm on my way there, but pick me up anyway." Something about her voice made me want to get it done, because she said, "You owe it to yourself."

And I would say today: Call the YWCA, and talk to Miss Linda; if not, talk to whomever is there.

Senator MIKULSKI. Well, I'm going to call the YWCA now and speak to Ms. Jackson. Could you elaborate on the Rakowski frame-

work that she just outlined? I know Ms. Brown expressed it so anecdotally, but what would you like to add to that?

Ms. Jackson. I would like to add that organizations like the YWCA and the American Cancer Society provide that structure that is needed to reach the population. And we have had years of expertise in reaching women, and we know that there is a lot of fear involved in going to get the mammogram. So we know that it is important for people to go in groups the first time. We know that it is important to remove the barriers of transportation. So there is a meshing of resources. We bring to the table the resources that we have, and we work with the Federal dollars that are given to us in addition, and it sort of leverages those dollars in a way, because we can provide the people, the volunteers, who can go on the day that the women go for the screening. We provide lunch. We try to make it a special day, and all of that specialness takes away some of the fear.

So I think the main point that I would like to make is that the partnership of the private and the public is important in the delivery of that health care service.

Senator MIKULSKI. Excellent. Now let's come back to that partnership.

Ms. Rakowski, one of the points you made is that the American Cancer Society value-added the $4 million. Do you feel that that is an essential component, or why did you add $4 million?

Ms. RAKOWSKI. First of all, in our State, the State health department and our division office——

Senator MIKULSKI. I mean, I think it is splendid, but my question is: Is private philanthropy a substitute for what public policy should be doing, or do we need that partnership?

Ms. RAKOWSKI. I think we absolutely have to have the partnership——

Senator MIKULSKI. Well, I want the partnership with the American Cancer Society and the YWCA and all the other groups that are involved.

Ms. RAKOWSKI. First of all, we absolutely need the partnership. And I think without that kind of involvement and commitment to this project, you would have organizations going about it in all different ways, not necessarily working together for the same common goal. The American Cancer Society in Michigan, when we first became aware of this funding, said we wanted to participate 100 percent. We had already had a wonderful partnership in doing some other programs, developing the Quality Assurance Standards Act within our State, etc.

One of the things that was of the initial RFP was that there had to be a match, a 1-to-3 match. In accepting that, it would be difficult for the health department to have come up with that match without working with us as an organization or local facilities or whatever. And it was very difficult to get local health care facilities and providers to initially sign on because of the fact that there is a lot of concern about liability, about, gee, I don't know if I can take on this health care burden, I don't know if we can afford to pay for this patient's treatment. A lot of those things did not instantly come about. So when we were going into communities and asking local public health—creating that partnership and allowing

them to use our resources as far as materials, our volunteers, which are the two primary things, our medical experts who are volunteers for us helped to forge those networks within local communities, sort of politically helped that.

Senator MIKULSKI. I want to go to this 1-to-3 match. Therefore, the value-added of the American Cancer Society helped meet the match. But also, what you are pointing out is that prior to this year, States were permitted to count donated diagnostic and treatment dollars as part of the State match, and now they can't.

Ms. RAKOWSKI. Correct.

Senator MIKULSKI. So you would tell us that that is one of the most crucial elements. So let's just say that as part of the follow-up it becomes in a community the "Committee of 100," consisting of physicians, radiologists and so on, who say that one per month, we'll do this, or whatever. Where they would be willing to do the pro bono, that now cannot be counted. So we are now in a double bind where there are, first of all, no "good guy" bonuses—is that essentially correct—where there is local effort.?

Ms. RAKOWSKI. That's correct.

Senator MIKULSKI. So we acknowledge cash, but we don't acknowledge in-kind services, and particularly in-kind services that meet the gaps in the program.

Ms. RAKOWSKI. Absolutely.

Senator MIKULSKI. In other words, the very thing that we need to be encouraging is the very thing that now, by regulatory procedure, we are discouraging.

Well, we are going to deal with that in the legislation, because I do believe we need to give either carrots or "good guy" bonuses, or "good will" bonuses, whatever, that then say if you are willing to do these kinds of pro bono things, that that will count. And I think those things not only build our health care response, but they build community.

Ms. RAKOWSKI. That's correct.

Senator MIKULSKI. I am concerned that too much of what we do does not build community, because the characteristics of what you are doing in the YWCA is community building and capacity building through the empowerment of women.

Ms. RAKOWSKI. Thank you. Absolutely.

Senator MIKULSKI. There are also other issues that you raise related to the mammogram quality standards. We are with you on that, and we are talking to Dr. Shalala herself to move those guidelines and regs, and we hope the Clinton administration picks up on that. And you also raised the concern that Federal laws may not be used for diagnostic and treatment services, and we agree that that is a gap.

We agree that it is a gap, but we also know that to have undertaken that would be comprehensive.

We want to say this is a first step. We know it is not the only step, and we want you to know that the Congress knows that. But we felt if we didn't take the first step, we would never get to the next step. So at this stage in our fiscal situation, and until we can get national health insurance, we won't have the comprehensive nature of it. But I want you to know that we know what you are

talking about, and I want to acknowledge that, and it will be a key component.

Ms. RAKOWSKI. Thank you, Senator.

Senator MIKULSKI. Ms. Rakowski, we want to thank you for what you are doing in Michigan, and that takes me to the YWCA.

Did the YWCA also put in their own money, or was it in-kind services and so on, the way Michigan value-added?

Ms. Jackson. Let me just ask Mary Dale—I think our input has been primarily in-kind services. It is in our operating budget.

Senator MIKULSKI. Oh, I am not minimizing it.

Ms. Jackson. I am just saying that in terms of actual dollars, we have obviously in our programs—ENCORE has always been a line-item part of our program in many of the associations.

Senator MIKULSKI. I understand, and Ms. Jackson, my question is do we know in the States where ENCORE is operating, has that been counted as part of the in-kind service.

Ms. Jackson. Oh, yes, indeed.

Senator MIKULSKI. So essentially, by your in-kind that comes from United Way efforts or private philanthropy, it enabled that to leverage to get the Federal funds.

Ms. Jackson. Exactly, yes. I also wanted to say that the participation of even dollars of these organizations is that it does offer the opportunity for communities and individuals to participate in something that they perceive as valuable. And people often have their own personal reasons for wanting to contribute money to a program, and I think we need to take advantage of that and offer them the opportunity through programs like this to do that. It is a community builder.

Senator MIKULSKI. I have one last question, Ms. Jackson. You say that the original collaborative agreement between the YWCA and its ENCORE program targeted 13 States. Then you go on to say that because it has been so enthusiastic, you now have collaborative activity in 23 States. Could you tell us what has generated this enthusiasm?

Ms. Jackson. I can only imagine, because I don't know. We only started this in the spring. But I think what happens is that when other YWCA associations in a State begin to see the generation of funds for program that they are also trying to do, that begins to spark their interest. They see the collaboration as a way to provide community programming that they want to do.

Senator MIKULSKI. What is it about it, though, that does it? In other words like "collaboration" and "coordination," and we are going to do partnerships—those are boilerplate. What is it? Is it something about the YWCA? What is it for 23 health departments to be enthused?

Ms. Jackson. As I said before, one of the things that we are just realizing, a value that we have, is the structure that we have always had in place. So you have the health department that is trying to reach people, and we've got the people and the structure in place to reach them. We have women who have always looked to the YWCA as a place for health and recreation. So right away, we have the credibility of the organization in health promotion.

So I think what it has provided is the avenue to reach underserved women. We have always done that, and this is a way of

doing that that seemingly is working and is having a great deal of success. That's the only thing that I can think of, that we have that credibility going for us, we have the structure there, and we have the volunteers, the people, the clients. So I think that that has been one of the reasons.

Senator MIKULSKI. First of all, I think you are exactly right. But words like "structure," again, if I could just elaborate——

Ms. Jackson. Do you want me to not use that and say something else?

Senator MIKULSKI. No. Because of the flooding, and the fact that I chair the FEMA appropriations, I am having a meeting later with the affected Senators and the President on that, so I am going to have to move the hearing along. That is why Senator Wellstone is not able to be here for the rest of the hearing, and other Senators—I don't know if Senator Harkin is back yet—Senators who ordinarily would be mesmerized by this type of hearing are the very ones who are really facing great tragedy in their own communities. I also wanted you to be aware of that. Senator Harkin had intended to participate. So as a co-member of this Kennedy committee and also on appropriations, we were really going to do a one-two thrust in this endeavor.

So what we are saying is this. It is not only cost. It is understanding the culture of the community. For some, it might be, first of all, just a day out of the house, a day out of the community, a bus trip. The President likes to take bus trips, and so does everybody else. And I will tell you when I'm out making my county visits, there is not an outlet in Maryland that does not know me on sight; there are sightings of me—because people want out, they want to get around.

So you go to the culture of the community, and it is not only an ethnic-based culture or the culture of a geography, like rural women. But I truly believe that among women ourselves is a subculture and that you are an expert in that. And it is therefore not seen as a chore that they must do; it becomes part of empowerment, part of fellowship or sisterhood, which we all like, and also, each one teaches one—but with each one teaching one, the group becomes bigger than the individuals. Isn't this part of it?

Ms. Jackson. You are exactly right.

Senator MIKULSKI. So it adds its own energy and vitality. I think that's it, and I think it is going to be crucial, then, when there is the outreach to physicians and other health care providers for referrals, that they also need to understand these community resources. I really think that needs to be part of it.

So I think that is really what the YWCA and the American Cancer Society are about. And the American Cancer Society is focused on prevention and detection and cure of cancer. The YWCA has focused on empowerment, from suffrage to civil rights, and now to health care. And what are the empowerment issues affecting women, I think is the crucial question.

We are going to need you because even if we do pass health insurance reform, that is a funding mechanism; it is not a delivery mechanism. So we'll be coming back to you, and we look forward to this partnership.

As a Senator who was one of the primary architects of this bill, I want to extend to the American Cancer Society and to the YWCA and to other groups like yourselves who have made this program not only possible through your funds and your sweat equity, but you help to make the program worthwhile.

I am very grateful for this, and I would like for you also to extend to your membership the appreciation of the Congress. So thank you.

Ms. RAKOWSKI. Thank you, Senator Mikulski.

Ms. Jackson. Thank you very much.

Ms. BROWN. Thank you, Senator.

Senator MIKULSKI. We now want to hear from the State health departments about what it takes to operate the bill, and one of the other groups that I want to acknowledge is the Komen Foundation, which has done an outstanding job nationwide. I believe their work in Texas will be one of the national models that we will want to learn from and duplicate. We want to acknowledge the fact that Elin Greenberg is here. We are very, very appreciative of her efforts.

We welcome Dr. John Southard, from the Maryland Office of Chronic Disease Prevention. Now, some might ask why is everybody here from Maryland? Well, first of all, I chair this subcommittee. [Laughter.] The second thing is that when they talk about the all-stars, they are not only on the baseball field. We feel we have an all-star program right here, and John, I am not going to do to you what Gaston did to Messina—you come on in and pitch.

We also welcome Margaret Mendez, from the Texas Department of Public Health, and David Momrow, from New York.

John.

STATEMENTS OF DR. JOHN W. SOUTHARD, DIRECTOR, MARYLAND OFFICE OF CHRONIC DISEASE PREVENTION, MARYLAND DEPARTMENT OF HEALTH AND MENTAL HYGIENE; MARGARET MENDEZ, DIRECTOR, BREAST AND CERVICAL CANCER CONTROL PROGRAM, TEXAS DEPARTMENT OF HEALTH; AND DAVID MOMROW, DIRECTOR, BUREAU OF ADULT AND GERONTOLOGICAL HEALTH, NEW YORK STATE DEPARTMENT OF HEALTH

Dr. SOUTHARD. Thank you very much, Senator.

We appreciate the opportunity to share with you our experience, and we have some suggestions for enhancing the program.

In Maryland, we estimate there are 260,000 women over 40 years of age who have never had a mammogram or have not had a recent mammogram, and these are the women we are trying to reach and help.

Our program was funded by CDC in January of 1992. In addition, we also have used local funds as matching funds to develop screening programs, and that began in 1991.

There are six basic areas of accomplishment I'd like to tell you about. The first area that we have succeeded in is creating public-private partnerships at the local level. We have awarded 24 grants to 24 local health departments, and we have contracts with 300 medical providers to provide clinical services such as mammogram,

clinical breast exams, Pap tests and pelvics. We also have 28 hospitals that are now participating in the program.

In terms of quality assurance, we have been able to have all 66 radiology facilities accredited by the American College of Radiology and all 44 cytology laboratories in compliance with the Clinical Laboratory Improvement Act.

"Reaching the unreached" is really the name of this program. That is what we are trying to do. One of the things we found to be especially important is having outreach workers from the special populations, women who actually live in the Hispanic and African American communities, who are older women, and we have been able to recruit 48 such women throughout the State and train them to help us reach the unreached women. This is also in collaboration with the formation of agency partnerships with the YWCA, the American Cancer Society, the AARP, the Hispanic radio stations especially in Montgomery County, Easter Seals, and the socioeconomically disadvantaged community.

So I think what has been said before is correct, that you need to work with the people in the community who are in touch with these women. They come in as a group, and they need to be encouraged as a group all along the line.

Also, we do have a public education campaign that has been funded because of the Governor's support of the cancer initiative in Maryland, and we have developed television, radio and newspaper spots, and we have an "800" number. Many people have heard about the availability of mammography screening through the "800" number and the aired TV spots.

In addition, in the first months of screening, we have screened 1,400 women with mammography, and we have done 1,100 clinical breast exams and 1,200 Pap tests using CDC funds. Sixty-eight percent of these women had not had a mammogram previously.

Also using State matching funds, we have screened another 7,500 women with mammography, performed 5,500 clinical breast exams, and done 1,200 Pap tests in 28 hospitals. So we have screened around 10,000 women at this point.

Now, it is really important to bring women back for rescreening, and that is another very important issue in this program. We have developed a computerized tracking system that is being used by all 28 hospitals in all 24 local health departments, and a system of local coordinators and primary care providers has been developed to ensure that women return for rescreening.

The next accomplishment is in treating the cancers found with state-of-the-art treatment. All of this effort really goes for naught unless we provide state-of-the-art treatment for these women once the cancers are found. This is not like an immunization program where you can go out and give a shot, and that's the end of it. We have to get the women into treatment.

We have been very blessed in Maryland to have funds to pay for treatment; by raising our cigarette tax, we were able to pay for treatment. Under the CDC program, we found seven breast cancers, two cervical cancers, and one pre-invasive cervical cancer. Under our hospital program, we found 37 breast cancers and two invasive cervical cancers, a total of 44 breast cancers.

All of these cancers have been diagnosed and treated with State funds. The diagnosis has been coordinated by a primary care provider. All cancers have been staged, and treatment planning is carried out with the help of an oncologist.

One of the things that we think this program can do is really improve the entire health care delivery system, and I think we have seen evidence of this in Maryland. We have definitely seen an increase in the availability of low-cost screening mammography in the State. When we first started these efforts, really the only mammography going on in Maryland was diagnostic mammography. We how have screening mammography available throughout the State. We have had a 50 percent increase in the number of mammography machines over the past 3 years, and in rural areas like Western Maryland, we have had a 140 percent increase. We have had a 40 percent increase in ACR accreditation of mammography facilities and a 22 percent increase in the number of mammography centers throughout the State.

So there has been a major impact. The private sector is seeing the importance of this, and they are tooling up to meet the demand.

Senator MIKULSKI. Doctor, could you move on to your recommendations, please?

Dr. SOUTHARD. Yes. The recommendations are that first of all, I think it is important to consider the amount of effort that it takes to run a program like this, and there are really four different compartments to this program, the way I look at it. The first is to provide adequate funding for staff who are responsible for outreach, follow-up and case management of diagnosed cases. In Maryland, we found that we need a minimum of two outreach coordinators, a full-time nurse coordinator, and full-time clerical people to reach a county of 200,000. This is fundamental. You have to have this basic structure in order to deliver the service. Once you have this in place, then the amount of money that is spent becomes much more cost-effective because the additional money you put into this program goes for direct screening because you have the infrastructure in place. The initial money, though, goes into establishing this infrastructure.

Also, we think additional funds are needed to pay for detection and all needed diagnostic services so that sufficient numbers of unreached women can be screened to impact on mortality. Even though it seems like a lot of money is going into this program, it is really just enough to get the infrastructure established. If you really want to reach large numbers and reduce mortality, there is going to need to be more money.

Also, I can't overemphasize that we need money for rescreening, and this is actually separate. Once you have screened a group of women, let's say 12,000 women a year, those women have to come back for rescreening the next year. That means you are no longer able to reach out to additional women and that your program is entirely devoted to rescreening. And it is from the rescreening that we reduce mortality and save women's lives. If we don't do rescreening, we won't save their lives.

Senator MIKULSKI. Doctor, I understand. I have to be at another meeting by noon, so I'm going to ask if you could move your rec-

ommendations along just a bit more crisply, and then I will turn to the other two witnesses.

Dr. SOUTHARD. Yes, certainly.

We would like to recommend that funding be continued on a permanent basis so that rescreening can go on. We would like the law to be clarified to indicate that all funds spent at the county level are within the 60 percent requirement and are not considered indirect costs.

We would like the law to be clarified to indicate that dollars spent by the State on outreach, detection, diagnosis and treatment can be used to match Federal funds. We would like the law to be clarified to indicate that private providers can be contracted with to provide screening and diagnostic services.

We would like to recommend that quality assurance requirements for mammography be consolidated under ACR guidelines as the national standard and that the legislation that you have already passed be implemented.

And then we would also like to recommend that a program be established exactly like the National High Blood Pressure Education Program that would develop a national consensus on detection, diagnosis and treatment guidelines for the Nation. There is a real lack of this, and this is a barrier.

This national program could bring together a national coordinating committee of agencies and societies; provide a national education program for both professionals and the public, and coordinate Federal agencies.

Thank you.

[The prepared statement of Dr. Southard follows:]

PREPARED STATEMENT OF JOHN W. SOUTHARD, M.D.

THE BREAST AND CERVICAL CANCER PROBLEM IN MARYLAND

Maryland has the second highest overall cancer death rate compared to any State in the Nation, and the ninth highest death rate from breast cancer. It is estimated that 3,400 Maryland women will develop breast cancer this year, and 850 will die from breast cancer. Breast cancer is the second leading cause of cancer death among Maryland women.

Early detection saves lives. There is a 92 percent 5-year survival rate for breast cancer detected in the local stages, and 100 percent of cervical cancer is curable if detected early.

ApproximatelY 260,000 (27 percent) of women over 40 years of age in Maryland have never had a mammogram or have not had a recent mammogram; 91,000 adult women have never had a clinical breast exam, and 121,000 adult women have never had a Pap test.

There are approximately 241,032 uninsured females 40 years of age or older in Maryland, of these, over 105,000 have not had a recent mammogram. These are the women targeted to be screened by Maryland's Breast and Cervical Cancer Program.

MARYLAND'S BREAST AND CERVICAL CANCER PROGRAM

Maryland received funding from the Federal Centers for Disease Control and prevention for the Breast and Cervical Cancer Program on January 31, 1992 and utilizing local funding began developing a hospital based mammography screening program in 1991. Since that time the following has been accomplished:

—Formation of public/Private partnerships at the local level:

—Grants have been awarded to all 24 local health departments to ensure that services are available.

—Local health departments have contracted with over 300 medical providers to provide clinical services (e.g. mammograms, clinical breast exams, Pap tests, pelvics).

—Twenty-eight hospitals are now participating in locally funded breast cancer screening programs.

—Quality Assurance

—All 66 radiology facilities are accredited by the American college of Radiology.

—All 44 cytology laboratories are in compliance with the Clinical Laboratory Improvement Act.

—Reaching the unreached

—48 outreach workers have been recruited and trained from the target special populations utilizing state funds and these individuals are now bringing unreached women to screening.

—A one million dollar State-wide Public Education Program was implemented using State funds; media spots have been developed and aired on TV, radio, in newspapers, an 800 number has been made available, a newsletter developed, media tours and interviews are being carried out.

—Formation of agency partnerships to reach the unreached such as with the YWCA, American Cancer Society, the Cancer Information Service, AARP, Hispanic Radio stations, Easter Seals, and the Socio-Economically Disadvantaged Committee.

—In the first months of screening, 1,432 mammograms, 1,136 clinical breast exams and 1,222 Pap tests were performed utilizing CDC funds. Annual screening should reach about 12,000 women using CDC funds.

—Sixty-eight percent of persons screened for mammography had been previously unreached (no recent mammogram or never had a mammogram).

—Utilizing State matching funds an additional 7,572 mammograms, 5,562 clinical breast exams and 1,217 paps have been performed by 28 hospitals throughout the State.

—Bringing in women for rescreening

—A computerized tracking system to follow women has been developed.

—A system of local coordinators and primary care providers has been developed to assure women return for rescreening.

—Treating cancers found with State of the art treatments

—Seven breast cancers and 1 cervical cancer have been found using CDC funds.

—Thirty-five breast cancers have been found with local matching dollars.

—All of these cancers have been treated using State funds.

—Diagnosis is coordinated by a primary care provider.

—All cancers are staged.

—Treatment planning is carried out with an oncologist.

—Increased capacity of private sector to deliver breast and cervical cancer services including:

—Increase in availability of low cost screening mammography from a few mobile units in the Baltimore area to sites throughout the State over the past 2 years.

—Fifty percent increase in the number of mammography machines over the past 3 years and in rural areas there has been a 140 percent increase.

—Forty percent increase in ACR accreditation of mammography facilities over the past 3 years.

—Twenty-two percent increase in the number of mammography centers in the State over the past 3 years.

GOALS OF THE PROGRAM—MEASURING SUCCESS

The Maryland program will be evaluating the success of the program by collecting information that answers the following questions:

—Effectiveness and quality of screening

—Are we reaching the previously unreached woman over 5O (never had a screen, no recent screen, no previous access to or availability of screening)?

—Are we utilizing high quality screening tests?

—Are we bringing these women back for annual rescreening?

—Are we finding small (<2cm) invasive breast cancers and precancerous cervical leisions in these rescreened women?

—Are we treating the cancers with state of the art treatment in a timely manner?

—Capacity Building/Institutionalization

—Are we increasing the capacity of public, private and voluntary sectors to deliver breast and cervical cancer services?

—Are we improving the quality of services in the private sector?

RECOMMENDATIONS

Based on Maryland's experience the following recommendations are made to improve the program:

—To provide adequate funding for staff who are responsible for outreach, follow-up and case management of diagnosed cases. In Maryland, we have found that we needed at a minimum two full-time outreach coordinators (recruited from the targeted special populations), a full-time nurse coordinator and a full-time clerical level person in each subdivision of approximately 200,000 persons.

—Provide additional funds to pay for detection and all needed diagnostic services so that sufficient numbers of unreached women can be screened to impact on mortality.

—Provide additional funds to pay for rescreening 50 that small invasive cancers can be detected and mortality reduced.

—Continue funding on a permanent basis so that rescreening will detect new cancers as they arise and reduction in mortality will be possible.

—Clarify the law to indicate that all funds spent at the bounty level are within the 60 percent requirement and are not considered indirect costs.

—Clarify the law to indicate that dollars spent by the State on outreach, detection, diagnosis and treatment can be used to match Federal funds to encourage States to provide funds in all areas of the program.

—Clarify the law to indicate that private providers can be contracted with to provide screening and diagnostic services under this program.

—Consolidate quality assurance requirements for mammography under ACR Guidelines and pass legislation requiring all mammography facilities to meet these Quality Assurance Requirements.

—Fund a National Breast and Cervical Cancer Education Program similar to the National High Blood Pressure Education Program that would:

—Develop national consensus guidelines for the detection, diagnosis and treatment of breast and cervical cancer.

—Bring together a national coordinating committee of agencies and societies.

—Provide a National Education Program for the public and professionals

—Coordinate Federal agencies.

Senator MIKULSKI. Thank you, Dr. Southard. We can see why the Maryland program has expanded. We estimated that it would be somewhere between 7,000 and 12,000, and you came right in at 10,000; well-done.

Let's turn to Ms. Margaret Mendez from Texas, which we also know has a very innovative program.

Ms. MENDEZ. Thank you, Senator Mikulski.

I am Margaret Mendez. I am the director for the Texas Breast and Cervical Cancer Program which is part of the Texas Department of Health.

I am pleased to be with you, and I have submitted written testimony and want to cover only three areas in that testimony.

First, I am glad to be able to tell you generally about our program and some of the areas where we would like to see some changes or something of a wish list.

First, Texas is one of the first of eight States selected as a comprehensive State. We were selected in the fall of 1991, and within 3 months were able to start the screening. The emphasis early on was on getting the program started. But one does not do that without having a great deal of support, and we have had that. As you indicated, early on, the Komen Foundation was absolutely an essential part of the Texas program and, of course, has been nationally also. And I know Elin Greenberg is here to submit some written testimony for today.

In addition, we work closely with the ACS at the State and local levels, and they also in Texas contribute a substantial amount of

money in terms of both public education and also professional education.

We are also one of the first States to go out and contract directly with the YWCA. They serve as an outstanding provider in our area and basically broker services in a fairly rural part of Texas and have brought in some private practitioners and have been very successful at that.

In designing the program, one of our main emphases was, as many people have said, that we did not want to manage a State program. We wanted to manage some local programs. We work with 35 different projects that provide services at more than 300 different sites, and basically, those contractors operate at a very local level.

We went out and specifically selected agencies that had access to the women that we are trying to target, that knew how to work with women who didn't normally come in for preventive care. They had access to the target populations, and they knew how to access diagnostic and treatment resources.

I know this is a very important concern of Congress, and we have worked very hard, and it is often a very case-by-case, step-by-step situation to try to make sure that a women gets the diagnostic and treatment resources that she needs. As I said, we have 35 different providers now, and they are operating out of about 320 different sites.

The other thing I wanted to emphasize is some of our preliminary findings. Some of the numbers that Dr. Wyatt gave you this morning will, I am sure, be updated shortly because all of us need to provide new numbers in the next couple of weeks.

In the last year and a half, we have seen about 27,000 women. As I said, I think we started fairly early, and that is why our numbers are relatively high. We know from the preliminary information we are looking at that these are the women who need care. About half of the women we see for both breast and cervical cancers are Hispanic, about a third are white, and about 17 to 20 percent are African American. We feel very strongly that we need to make more inroads with the African American population. One way to do that is to have increased funding so we can attract providers who know how to reach that population.

We are especially pleased that many of the women receiving services are actually the targeted age groups that we want. With breast cancer, 50 to 60 percent of them are 50 years of age or older; with cervical cancer, about half of them are 40 and older—a group that is very hard to bring in for cervical screening.

We also know that about 70 percent of the women who are coming in for their first mammogram have never had a mammogram before, even though half of them are 50 years of age or older. So we know that we are reaching the right group. In the cervical area, on the average, about 25 percent have never had a Pap test, or don't know if they have ever had a Pap test, and this in spite of the fact that cervical screening and Pap tests are so inexpensive and so well-funded both by the State and the Federal Government.

When we do screening, we have found that about a quarter of them are going to need some diagnostic follow-up. And, although most of that ends up being short-term, benign follow-up, that

means that every fourth woman, you are going to need to follow very closely through the system, and someone is going to have to spend very hands-on time with that individual to get her through the system, and sometimes through several different systems.

As of now, we have identified more than 200 cancers. That has increased substantially over the last 6 or 7 months. We think that we are making inroads into a population that we were not seeing early on—probably a population that is just hearing more about the program now.

Last, I would like to talk about some of our wish list. First of all, we are very pleased to see the amendment that private entities be considered as participants in this program. The health care delivery system in Texas, and I am sure in all States, has to consider private entities whether they are profit or not-for-profit. We cannot deliver this program unless they can be providers.

Second, we again want to emphasize the great time and money that has to go into diagnostic and follow-up care. We would like to see a little bit more flexibility in terms of the services that can be covered. Once again, our providers spend a lot of time trying to access different diagnostic services in their communities. Again, the matching requirement is a big concern for us. We agree with the philosophy and the thoughts behind the matching requirement, but even if you tripled the size of this program, we would not be able to increase our match, so essentially we would have to stay at level funding. And, as Dr. Southard said, we would basically continue to rescreen the same women.

I think one of the last figures I submitted in the testimony indicated that even with the numbers that we have reached, we are reaching less than 2 percent of those in Texas who are potentially eligible. We know that there is no way that we could see 1.5 million women. There is no infrastructure for that, and some of those would never come in or want the service. But we think we need to be able to substantially increase that proportion.

Finally, just in general, on expansion of the program, it is very expensive to reach women in rural areas, and as you reach one group of women, it is going to get more expensive to reach some others. So not only for Texas, but we would like to see expansion of the program in general.

I thank you very much and would be pleased to answer any questions.

[The prepared statement of Ms. Mendez appears in the appendix.]

Senator MIKULSKI. We thank you, Ms. Mendez. We know that a good part of the success—and I know we are about to hear from New York—is due to Governors who have been absolutely committed to this type of endeavor. I know Governor Schaefer has his special Task Force on Cancer Prevention, Detection and Treatment; I certainly know of Governor Annie's longstanding commitment to this in Texas. This is a topic that she and I have discussed personally, and now I am glad to meet the lady behind all her bragging to me about her program. And of course, we know of Governor Cuomo's deep commitment as well.

Now, before you proceed, Mr. Momrow, I know that Dr. Southard is an M.D., but what is your background, Ms. Mendez?

Ms. MENDEZ. I have an M.P.A. in health administration. My background is in clinical services, clinical administration.

Senator MIKULSKI. And you are an M.P.H., Mr. Momrow?

Mr. MOMROW. That's correct, Senator.

Senator MIKULSKI. I think what we often overlook in the whole health care debate is that it is not only reimbursement for medical treatment, but it is the public health model, and each one of you have trained in the administration of public health models, which makes the reimbursement system effective.

So why don't we now hear from New York.

Mr. MOMROW. Thank you, Senator, and in the interest of time, I will abbreviate my comments.

Senator Mikulski, it is my honor to represent the American Public Health Association and the Association of State and Territorial Chronic Disease Program Directors today.

Senator MIKULSKI. Oh, I see. So in addition to your hat as the big New Yorker, coming from the Big Apple, you are representing a whole orchard. [Laughter.]

Mr. MOMROW. Yes. I wear three hats today. Thank you.

My name is David Momrow—that is "Mom" as in "mother" as opposed to "Mam" as in "mammography"—and I serve as the acting director of the Bureau of Adult and Gerontological Health with the New York State Department of Health in Albany.

I am especially pleased to speak with you about the Breast and Cervical Cancer Mortality Prevention Act of 1990, and I urge you to reauthorize this critical legislation.

As you know, Senator, this program has been fully implemented in 12 States. Although New York State is not currently receiving Federal support for a comprehensive breast and cervical cancer control program, we certainly hope to receive such funding very soon.

As far as breast cancer is concerned in New York, it is a tremendous burden. It is the most common cancer found in women in New York State, with more than 10,000 new cases and 3,700 deaths reported each year. That represents over 25 percent of all malignancies occurring in women.

In comparison to breast cancer, cervical cancer has a smaller impact on the health of women in New York State. Incidence rates are comparable to those reported for the Nation, and mortality rates are consistently lower, and yet every one of the 340 cervical cancer deaths that occur in New York each year are preventable, because this disease is curable when detected in its earliest stages.

We are extremely grateful, Senator Mikulski, for your sponsorship, or as you more appropriately put it, for serving as the architect of the Breast and Cervical Cancer Mortality Prevention Act of 1990. I can assure you that the public health community also appreciates the funding provided through the program which has enabled 12 States to begin offering comprehensive breast and cervical cancer control services. It has also been extremely helpful that planning grants have been made available to an additional 18 States, including New York, for development of the surveillance, public and professional education, outreach, tracking, follow-up and quality control components that must be in place along with screening for an effective program.

We must not suffer under the illusion, however, that we have a national comprehensive breast and cervical cancer control program today. Just as it would be unacceptable for immunization, sexually transmitted disease, and tuberculosis control programs to be supported in only 12 States, it is equally unacceptable to the women of this country to have comprehensive breast and cervical cancer control programs in only 12 States.

I would like to advise you today that the States are not only supportive of the continuing authorization for this program but are ready for a significant increase in the annual appropriation for this program in the amount of $200 million as requested by the American Public Health Association. This will permit the Centers for Disease Control and Prevention to expand support for all States for provision of comprehensive breast and cervical cancer control services.

While we are extremely hopeful about the favorable impact of research in such areas as molecular biology and contributing to the earlier detection, more favorable prognosis, and perhaps even prevention of breast cancer, we must invest more significantly in what we currently know about reducing mortality from this dreaded disease. In this decade, an estimated 2 million women in this country will learn they have breast or cervical cancer, and more than half a million women are expected to lose their lives. A disproportionate number of these deaths will occur among women of low income.

Mammography screening remains the single most effective method of detecting breast cancer in its earliest, most curable stages. The Pap test introduced in the 1940's provides the means to prevent virtually all deaths from cervical cancer. It will be a tremendous let-down for the women residing in the 38 States not currently receiving Federal comprehensive breast and cervical cancer dollars if Congress is unable to extend this critically important program to all States in the very near future.

We are fortunate in New York to have an annual State appropriate supporting a breast cancer detection and education program. We have actually had a breast cancer detection and education program since 1987, and the current State appropriation is $2.5 million. And I would like to reiterate your acknowledgement of Governor Cuomo's support of this program. In fact, Mrs. Cuomo serves as the co-chair of our statewide breast cancer advisory committee.

We are also privileged to have such competent and dedicated health professionals as Dr. Harold Freeman, chief of surgery at Harlem Hospital and former president of the American Cancer Society. It is so discouraging, however, to visit Harlem Hospital and to see Dr. Freeman's slides showing the fulminating breast cancer tumors for low socioeconomic women who come to the hospital for the first time during the latter states of breast cancer when the prognosis for survival is so poor. Fortunately, the Breast Examination Center of Harlem is now offering these culturally sensitive services to the African American women of central Harlem, but we must also have the resources, however, to extend them to the women of Bedford-Stuyvesant, to the rural poor of the Adirondack region, and numerous other communities throughout New York State and indeed throughout our country.

This is a very exciting time in our country as the issue of health care reform has been elevated to the highest levels of our government for consideration. I would suggest, however, that even if we could create a new health care delivery system overnight, characterized by universal access and a package of minimum benefits including mammographic and Pap screening, we would still need a program of this nature. We have already learned the unexpectedly small role that access plays in the screening equation. Were access assured, we would still need to educate women to find and motivate the underserved, the solidify the commitment of health care providers to early detection and to enhance their skills and to invest necessary and considerable time to connect women with abnormal results to diagnostic testing and treatment.

In fact, as an aside, I might point out that Dr. Freeman in Harlem Hospital has developed a concept of a patient navigator because screening, as my colleagues have pointed out, is not the end stage. If a woman is detected as having a positive mammogram, or a mammogram with suspicious findings, there is a whole complex path through which people have to navigate or fed their way through diagnostic testing and whatever the recommended treatments might be, and the follow-up tracking systems and initiatives are so important.

This public health context is essential to the success of comprehensive early disease detection and control programs.

In summary, I ask for your reauthorization of the Breast and Cervical Cancer Mortality Prevention Act and for adequate funding of this program to help reduce the impact of these diseases on the 2 million American women who will be diagnosed this decade. They just cannot wait for incremental funding to support a few new States each year.

Thank you, Senator.

[The prepared statement of Mr. Momrow follows:]

PREPARED STATEMENT OF DAVID C. MOMROW, M.P.H.

Madame Chairman and distinguished members of the committee. It is my honor to represent the American Public Health Association and the Association of State and Territorial Chronic Disease Program Directors today on the critical issue of breast and cervical cancer control. My name is David C. Momrow and I serve as the acting director of the Bureau of Adult and Gerontological Health with the New York State Department of Health in Albany. I am especially pleased to speak with you on behalf of the "Breast and Cervical Cancer Mortality Prevention Act of 1990" and I urge you to reauthorize this critical legislation. As you know, the program established by this law has been fully implemented in 12 States. Although New York State is not currently receiving Federal support for a comprehensive breast and cervical cancer control program, we certainly hope to receive such funding very soon.

Let me tell you about the burden of breast cancer in New York. It is the most common cancer among women in New York State, with more than 10,000 new cases and 3,700 deaths reported each year. Breast cancer represent over 25 percent of all malignancies occurring in women.

Mortality, although relatively stable, remains a concern. New York State ranks fourth among all the States in breast cancer mortality for white women. Despite lower overall incidence rates, black women experience breast cancer mortality rates approaching those observed in whites, along with lower 5-year survival. A substantial proportion of these deaths represents failures of our health care delivery system and public health strategies in educating and motivating women and providing comprehensive breast cancer screening and treatment services.

In comparison to breast cancer, cervical cancer has a smaller impact on the health of women in New York State. Incidence rates are comparable to those reported for the Nation, and mortality rates are consistently lower. Yet, every one of the 340 cer-

vical cancer deaths that occur each year in New York is preventable, because this disease is curable when detected in its earliest stages. Invasive and in-situ cervical cancer incidence rates tend to be higher in New York City than elsewhere in the State. Invasive incidence and mortality rates in blacks and Latinas are 2 to 3 times higher than those observed in whites, with increases most pronounced among middle-aged and older women.

We are extremely grateful Madame Chairman for your sponsorship of the "Breast and Cervical Cancer Mortality Prevention Act of 1990." On behalf of the American Public Health Association, I can assure you that the public health community also appreciates the funding provided through the program which has enabled 12 States to begin offering comprehensive breast and cervical cancer control services. It has also been extremely helpful that planning grants have been made available to an additional 18 other States, including New York, for development of the surveillance, public and professional education, outreach, tracking, follow-up and quality control components that must be in place along with screening for an effective program.

We must not suffer under the illusion, however, that we have a national comprehensive breast and cervical cancer control program today. Just as it would be unacceptable for immunization, sexually transmitted disease and tuberculosis programs to be supported in only 12 States, it is equally unacceptable to the women of this country to have comprehensive breast and cervical cancer control programs in only 12 States.

I would like to advise you today that the States are not only supportive of the continuing authorization for this program but are ready for a significant increase in the annual appropriation for this program in the amount of $200 million as requested by the American Public Health Association. This will permit the Centers for Disease Control and Prevention to expand support to all States for provision of comprehensive breast and cervical cancer detection control services.

While we are extremely hopeful about the favorable impact of research in such areas as molecular biology in contributing to the earlier detection, more favorable prognosis, and perhaps even prevention of breast cancer, we must invest more significantly in what we currently know about reducing mortality from this dreaded disease. In this decade, an estimated 2 million women will learn they have breast or cervical cancer, and more than half a million women are expected to lose their lives. A disproportionate number of these deaths will occur among women of low income.

Mammopraphy screening remains the single most effective method of detecting breast cancer in its early most curable stages. The Papanicolaou (or Pap) test, introduced in the 1940's provides the means to prevent virtually all deaths from cervical cancer.

It will be a tremendous let down for the women residing in the 38 States not currently receiving Federal comprehensive breast and cervical cancer dollars if Congress is unable to extend this critically important program to all States in the very near future.

I would also like to discuss the diverse characteristics of the women who benefit from these programs. New York State women, for example, represent a myriad of cultural, ethnic and racial groups, increasing significantly the challenge inherent in public education, targeted outreach and appropriate provision of services. Currently, we are gathering information about the beliefs and practices of five sub-populations: rural elderly women, migrant workers, American Indians, Latinas and older African-American women—through our CDC funded planning grant. This information will be used in targeting our educational efforts to these special populations.

We are fortunate to have an annual State appropriation supporting a Breast Cancer Detection and Education Program in New York State. We are also privileged to have competent, dedicated health professionals such as Dr. Harold Freeman, chief of medicine at Harlem Hospital and former president of the American Cancer Society. It is so discouraging, however, to see Dr. Freeman's slides showing the fulminating, breast cancer tumors for low socioeconomic women who come to the hospital for the first time during the later stages of breast cancer when the prognosis for survival is so poor. Fortunately, the Breast Examination Center of Harlem is now offering these culturally sensitive services to the African-American women of Central Harlem. We must have the resources, however, to extend them to the women of Bedford-Stuyvesant, the rural poor of the Adirondack Region and numerous other communities throughout New York State, and indeed, throughout the country.

This is a very exciting time in our country as the issue of health reform has been elevated to the highest levels of our government for consideration. I would suggest, however, that even if we could create a new health care delivery system overnight,

characterized by universal access and a package of minimum benefits including mammographic and pap screening, we would still need this Federal program.

We have already learned the unexpectedly small role access plays in the screening equation. Were access assured, we would still need to educate women, to find and motivate the underserved, to solidify the commitment of health care providers to early detection and to enhance their skills, and to invest necessary (and considerable) time to connect women with abnormal results to diagnostic testing and treatment.

There is a public health context that is essential to the success of comprehensive early disease detection and control programs.

In summary, I ask for your reauthorization of the Breast and Cervical Cancer Mortality Prevention Act and for adequate funding of this program to help reduce the impact of these diseases on the 2 million American women who will be diagnosed this decade. They just can't wait for incremental funding to support a few new States each year.

Thank you very much for the opportunity to discuss these issues with you today.

Senator MIKULSKI. Thank you very much, Mr. Momrow, and all of you for your testimony.

I am just going to go over a question or two, because in each one of your testimonies, you not only cover what you have done, but I think you gave us really specific recommendations on how to improve the program.

What emerges are the issues around culture, language and transportation. Could you elaborate in each one of your areas—first of all, you, Mr. Momrow, speaking for the whole association—how you dealt with that? I know you outlined very clear that this was crucial, but even if we had national health insurance reform, we would need these public health initiatives to see that the insurance reform was taken advantage of.

Mr. MOMROW. Well, Governor Cuomo is always fond of talking about the "family" of New York. New York is just reflective of our entire country. We have such considerable diversity in our population. We have 4 million women over 40 years of age. We estimate that 250,000 of those women do not or have great difficulty in speaking English, which is a reflection of considerable diversity in immigrant populations and so forth, and it takes a great deal of effort through indigenous community groups and through outreach to establish——

Senator MIKULSKI. But tell me what you have done to overcome those barriers. Outreach is an abstraction.

Mr. MOMROW. OK. What we are doing is we have staff people dedicated to working with community groups, serving those respective populations, with a focus on Latinas, American Indian women, rural women and older African American women, to determine what the cultural barriers are in terms of fear of mammography, or access issues, or just general information about their risk and so forth, and attempting to develop appropriate messages and channels—not to take the standard pamphlet or booklet or whatever, but to start from scratch and learn what the appropriate messages are, and other channels as well—specific radio stations, for example, that serve particular populations, developing target group specific materials and messages—but also to work very closely with the community groups that are in the communities and the network of community leadership.

Senator MIKULSKI. Ms. Mendez?

Ms. MENDEZ. I think you have to approach it at two different levels, and then you never stop doing whatever it is you start doing.

Organizationally, you need to pick the right agencies. You need to pick agencies that are where people are. For example, if they are providing cervical screening, they need to identify the women within that cervical screening program and get them over for mammogram. They already know how to talk to them. And then you pull those providers together, frequently, and have them talk to each other about what things have worked.

A lot of the things that we tried did not work because we have so many different communities. Some of the things that were tried by some providers didn't work, so they had to go back and try two and three different approaches, whether it was going to churches, or doing talk shows or whatever. You do whatever is appropriate in the community.

Senator MIKULSKI. What did you think would work that didn't?

Ms. MENDEZ. For example, going to churches. In some places, it has worked, and in others it has not. Church isn't necessarily the focal point in every community, and those are not necessarily always the folks we are trying to reach. It just varies with the community. In more rural communities, that is the place where you get information. In an urban area like Dallas, we try to go to the Federally-qualified community health centers that already have that target population—they are already seeing them for hypertension, and while they have them there, the doctor says come on over, we are having a mammogram clinic. This is how you get into it. So you try several different approaches, you reinforce with community organizations like ACS, YWCA, or anyone who is out there. What works varies by community.

Senator MIKULSKI. So the framework is that you meet people where they are and not where you think they ought to show up; isn't that right?

Ms. MENDEZ. Absolutely.

Senator MIKULSKI. Which goes to the "Y" approach, and the Komen Foundation and other of the nonprofit groups, whether they be religious or whatever is their function.

Ms. MENDEZ. Absolutely.

Senator MIKULSKI. Dr. Southard, did you want to comment? You know, when people think of Maryland, everybody thinks it is crabcakes, beer and the Orioles. But as you travel around Maryland, you find that we have a very diverse immigrant population, ranging from Hispanics to new refugees from the Soviet Union and Eastern Europe, to newcomers from around the world.

Dr. SOUTHARD. That's right. And I think you have to identify the organizations that are working with these special population groups and join in partnership with them. I think you have to have staff who are members of these special populations and who are bilingual. Very fortunately, Dr. Herrara in Montgomery County is an Hispanic physician and has a radio station to the Spanish community. These sorts of things are what you need to do.

Senator MIKULSKI. Well, I think that really covers the ground. Let me say this. First of all, I could talk with each of the panels all day long. Let me tell a real quick story about me.

Twenty-5 years ago, after the assassination of Dr. King and Senator Kennedy, it was during that time that I was working as a community organizer in Baltimore. I was working the War on Pov-

erty, where I was the assistant chief of community relations, and I was the architect of the decentralization of the welfare department into neighborhoods; I worked with legal aid lawyers; I had supervisors telling me I didn't have a "therapeutic" personality, but I was out there.

I was on my way to getting a doctorate in public health when I went, at the request of another social worker, to a meeting at a Catholic church because that community was going to be threatened by an expressway, and they were afraid to fight the machine. But they were at the church—and the rest is history. I helped organize a community organization in my neighborhood right after the Baltimore riots. We had a biracial group, where the other side of a segregated city and the African American community was threatened by the expressway. We formed a citywide group, and we called ourselves "SCAR"—of course, we had to have a militant name—and the African American community had a group called "RAM," and we put together a citywide coalition called "MAD."

I won't tell you the story, but where you all see the new ball park, the Inner Harbor, and so on, would have been an expressway. It was the neighborhood people who accomplished that.

And I never went on to get my doctorate in public health. No matter whether I wear this little toga the people of Maryland have given me or not, I am a public health person.

So I want to thank you for your innovation and your efforts in putting this program to work, as I feel a colleague with you in this as well as the community organizations that have participated in this. And we want to stay the course, first of all, to sustain and expand what we have. We think your lessons learned and your wish list and so on are extremely helpful. We feel one of the most important things we can do now is rework what counts as the in-kind contribution, because if we can get rid of some of these regulations, and do it statutorily, in fact, whatever gains we can make financially, you then could expand your program where it would enable you to stay the course in your own States. And rescreening is important, but I know that as public health folks, you not only want to rescreen, but you want to continually expand the outreach based on the experience.

So we think that your lessons learned from the match, the administrative aspects and so on are well-taken, and we are going to work on that.

Again, I want to conclude by thanking all of you and all of the men and women who work in public health, and I will just close by saying that I know that we are not comprehensive. Again, this is the first step, not the only step. We have got another whole next step to take care of, but we want to be able to sustain this program, to expand this program, and also give the "good guy" bonuses at the local level where you can do that.

So we'd like to thank you for that. We think we've gotten excellent information out of today's hearing to improve it, and we hope you have found this participation equally as informative.

Again, many, many thanks.

This hearing is concluded, and the subcommittee is in recess subject to the call of the chair.

[The appendix follows:]

APPENDIX

Prepared Statement of Elin Greenberg, Chairman, The Susan G. Komen Breast Cancer Foundation, Inc.

Good morning. I am Elin Greenberg, 1993 Chairman of the Susan G. Komen Breast Cancer Foundation, headquartered in Dallas, TX. The Komen Foundation is a national network of volunteers working through local chapters and RACE FOR THE CURE events in 40 cities, representing 24 States and the District of Columbia. Our mission is to eradicate breast cancer as a life threatening disease by advancing research, education, screening and treatment.

In the 1990's, about 2 million women will be diagnosed with breast and cervical cancer. In 1992 alone, these two cancers claimed the lives of over 50,000 women. Incidence and mortality rates remain highest among women who are low-income, members of minority groups and medically underserved. With education, early detection and appropriate follow-up, we can reduce the rate of mortality from breast cancer by 30 percent and reduce the cost of treatment by 80 percent.

The best Federal program to effect these reductions is the Breast and Cervical Cancer Screening Program of the Centers for Disease Control and Protection (CDC), but it is woefully underfunded. The Komen Foundation urges reauthorization of the CDC's screening program with an increased funding level of $200 million for Fiscal Year (FY) 1994 and such sums as will be necessary for FY 1995 through 1998.

KOMEN AND CDC: ACCESS TO COMMUNITY-BASED SUPPORT

The Komen Foundation was founded in 1982 by Nancy Brinker in memory of her sister, Susan G. Komen, who died of breast cancer at age 36. Since then the Foundation has grown into a thriving, vertically-integrated, volunteer-driven organization that works actively at the national, State and local levels to eradicate breast cancer as a life threatening disease. With over $19 million raised since its inception, the Komen Foundation is one of the largest private foundations funding breast cancer research, education, screening and treatment efforts. The Foundation's leaders are national advocates on breast cancer issues. Founder Nancy Brinker has served on the National Cancer Advisory Board, the President's Cancer Panel and chairs its Special Commission on Breast Cancer. Komen representatives have collaborated with other cancer groups to secure substantial increases in federal funds for breast cancer research, achieving a total of $406 million for FY 1993 (or $236 million in new funds). We also played a major role in the enactment of the Mammography Quality Standards Act; of 1992, which I will address later in my testimony.

The Komen Foundation supports a balanced program of research to find the cure for breast cancer, screening for better detection of the disease, and programs to promote better education and awareness of self-examination, detection and treatment options. Vital and central to our program is our commitment to meet the needs of the underserved, minorities and those least able to access health care. Through a variety of community-based efforts, the Komen Foundation works to eliminate barriers, whether financial, institutional, cultural, or a combination of all of these and more. The Foundation's particular strength is its ability to create coalitions of health care facilities and providers, private/public partnerships, and volunteer-staffed model programs to provide the education and awareness activities that improve access to care for breast health for all women.

One example of a very successful Komen effort is its national helpline (1-800-I'M AWARE) using trained volunteers to assist callers with breast cancer issues and related concerns. Another example is the Leadership Summits on Breast Cancer which the Komen Foundation has sponsored with the National Cancer Institute since 1989 to increase and promote public/private partnerships and encourage community-based and regional programs for awareness, screening, and treatment of breast cancer. The Foundation also has cosponsored The Biennial Symposium on Minorities and Cancer, about which I will provide more information in a moment.

Key to the Komen Foundation's phenomenal growth in recent years has been its highly successful RACE FOR THE CURE series of 5K/1 Mile race walks across the United States. From the first race in Dallas in 1983, the series has ballooned to races in 35 cities across the country with an expected 125,000 participants in 1993. The national RACE FOR THE CURE, just run in Washington, DC. on June 19, attracted 13,000 participants and thousands of additional supporters. Most important for our discussion here are two facts:

1. Komen requires, as a precondition for approval as a race city, that the applicant city build a coalition of hospitals and other health care providers not only to participate in conducting the race but also, afterwards, to assist in coopera-

tive efforts to provide screening, referrals and treatment to underserved women; and

2. Requires that 25 percent of race proceeds fund national research grants and 75 percent of the money remain in each city to fund screening (in States without CDC programs), establishment of breast health centers, bilingual outreach, hospital programs such as "patient navigators", to help underserved women through the diagnosis and treatment process, and other efforts to bridge the gap between detection and treatment of breast cancer.

It is the Komen Foundation's emphasis on community-based activities that attracts its support for the CDC Breast and Cervical Cancer Screening Program. From our experiences with our RACE FOR THE CURE series, we know how important it is to make all hospitals and other health care providers work together to provide services to medically underserved people. In our view, a particular strength of the CDC program is the capacity-building funded through planning grants to states. Pursuant to such grants, States have engaged in exceedingly important strategic planning to implement the best possible screening program based on the particular State's available health care facilities.

NATIONAL STRATEGIC PLAN

During the years I have been a full-time volunteer with the Komen Foundation, I have been fortunate to participate in information gathering and group planning for breast and cervical cancer programs on a national and, more recently, on a State level. I represented the Komen Foundation on the National Strategic Planning Task Force for Breast Cancer, and also served on the 16-member Texas Strategic Planning Committee for Breast and Cervical Cancer.

When the National Strategic Plan was released to the public recently, I was pleased that Secretary Donna Shalala of the Department of Health and Human Services pledged the "best efforts" of CDC, NCI and the Food and Drug Administration (FDA) to work in partnership with voluntary organizations to achieve the stated goal to reduce mortality and morbidity from breast and cervical cancer. The Komen Foundation is one of the voluntary organizations devoted to achieving this goal. We believe, however, that all of the strategies in this National Plan will fail if we do not find mechanisms to educate and screen the appropriate populations, no matter which state these populations inhabit. Access is key.

BIENNIAL SYMPOSIUM ON MINORITIES AND CANCER

The access message reverberated in April, 1993 at the Fourth Biennial Symposium on Minorities, the Medially Underserved and Cancer which the Komen Foundation cosponsored in Houston, TX. The Symposium brought together health care providers, patient advocates, representatives of health care related businesses, educators, members of groups traditionally lacking access, and officials from the NCI, CDC and the U.S. Surgeon General Designee, Joycelyn Elders. The 4-day conference presented us all an extraordinary opportunity to examine existing health conditions and health care delivery systems, and present successful model programs.

Several important presentations at the Symposium recited the disturbingly high incidence and mortal it for cancer among minority populations in the United States. Other presentations, including one by the CDC on its Breast and Cervical Cancer Screening Program, emphasized the need to expand access to the medically underserved. CDC stressed the importance of coordinating its screening program with community-based efforts by providers and private organizations like the Komen Foundation, to help underwrite diagnostic treatment and other services which aid patients as they navigate a sometimes bewildering health care system.

THE CRITICAL ROLE OF SCREENING

While screening cannot prevent breast cancer, detecting the disease in its earliest, most treatable stage can significantly reduce suffering and death. Prior to the enactment of the Breast and Cervical Cancer Act of 1990, only four states received screening funds. By 1992, 12 States were involved in screening women for breast and cervical cancer and another 18 were engaged in planning and capacity-building for their screening programs. The CDC testified at the Biennial Symposium that as many as 17 States may be funded for screening by the end of this summer. But what about all of the underserved women in all the other States who have no access whatsoever to screening?

KOMEN RECOMMENDATIONS

1. Authorization of $200 Million for Fiscal Year 1994

Since 1990, the CDC's National Breast and Cervical Cancer Early Detection Program has been the primary mechanism in selected States to funnel Federal funding, matched by State funds, to support State health departments' efforts to educate, screen, follow-up and access quality assurance efforts in those States. The House of Representatives provided an FY 1994 appropriation level for the CDC program of only $72 million, nearly $30 million shy of the current authorization level of $100 million. While the House reauthorization bill would increase the FY 1994 authorization level to $135 million, that level still is inadequate to address the needs of all the states to screen their populations not otherwise served.

The Susan G. Komen Breast Cancer Foundation urges the Senate to increase the authorization for the CDC's Breast and Cervical Cancer Screening Program to $200 million for FY 1994, and such sums as are necessary for FY 1995-1998. With appropriations to match these authorization levels, the CDC could expand its programs to all 50 States to screen 30 percent of all uninsured women in each of those States as well as the territories. Each State would be allocated funds for screening and infrastructure costs (i.e., including public education, professional education, quality assurance, and surveillance), as well as referrals and limited follow-up.

The CDC must be able to continue building a nationwide infrastructure as the conduit for awareness, education and empowerment of citizens. This will be particularly important when health care reform changes the terminology, but not the needs, of those least able to provide for themselves and their families. The CDC's infrastructure built today will be the foundation for implementation and delivery of the full spectrum of prevention and education programs in the future.

2. Expand Access and Outreach Efforts

In addition to increased funding, the Komen Foundation recommends that particular attention be given to the issue of "access" to CDC screening once the program is implemented in any given State. The program must bridge the gap between "availability" and "accessibility". Make no mistake; they are not the same. For example, M.D. Anderson Hospital in Houston, TX is the NCI-designated comprehensive cancer center for Texas residents. Anyone in Texas can receive care at that center—what we call "available" care. If you happen to live in Eagle Pass or Abilene, TX, however, M.D. Anderson is definitely not "accessible" care. In Texas, we proposed that the State Department of Health contract with care providers in rural, remote areas to utilize CDC funds and plans to provide screening to underserved women who need it.

One of the most exciting discussions in our strategic planning for the program in Texas was the exploration of possibilities of using state-of-the-art technology to link the professional community and health care providers in rural and remote areas to share ideas, information and techniques. We hope that CDC funds will be-available for use of high technology communication links.

Low-tech, but equally important to underserved populations, are programs that help patients with minimum education and few English language skills to navigate the health care system. This is an area where the Komen Foundation and groups like it can be helpful as private partners working with the CDC to ensure access to screening, referrals and then to the appropriate treatment options available to the underserved. The Komen Foundation's RACE FOR THE CURE series has afforded funds to a number of cities' hospitals with patient navigator programs (Greater Southeast Hospital in Washington, DC. is a good example). The Foundation also has supported the Bridge Program in Dallas where individual doctors rotate in providing pro bono care to underserved patients. We urge the Senate Committee to consider language in the reauthorization bill or report that would permit some CDC support for patient navigator programs at a minimum.

3. Screening Quality Assurance

The Komen Foundation's final recommendation addresses one of the six major components of the National Strategic Plan: quality assurance for breast cancer screening. The plan's objective here is to ensure consistent, high-quality breast cancer screening throughout the entire process of obtaining, interpreting and reporting mammogram results. There is no better way to meet this objective than for the Federal Government to implement immediately the Mammography Quality Standards Act of 1992! The successful implementation of this Act will be integral to the effectiveness of CDC's breast cancer screening programs in every State across the United States. Screening is of no use, and actually can be tremendously detrimental, if the results are misread by unqualified, uncertified technicians.

The Komen Foundation is greatly distressed that no Federal regulations are in place, and none have even been proposed, to implement the critically important pro-

visions of the Mammography Quality Standards Act (MQSA). We urge the Senate Committee on Labor and Human Resources to impress upon Health and Human Services Secretary Donna Shalala and Food and Drug Administrator David Kessler the need to move forward in drafting regulations without further delay or further substantive statutory changes. We suggest instead that the affected agencies and other interested parties get together immediately to discuss how the existing voluntary standards developed by the American College of Radiology can be used as the model for federal quality standards for mammography screening. The Komen Foundation has worked too hard on the federal MQSA (as well as State laws mandating mammography quality standards and insurance coverage for screening mammograms for women 35 and over) to tolerate much more delay.

CONCLUSION

The Komen Foundation fully recognizes the severe budget constraints under which the Congress is operating. Such constraints make critical the need to invest wisely the scarce dollars we do have. To spend money on screening near-term to save money and lives long-term is the wisest decision. Last year witnessed the loss of 46,000 women's lives to breast cancer alone. The financial impact of their treatment, lost wages, loss to their families of care givers, and loss to our economy of trained, productive and valuable Citizens cannot be easily dismissed. Let us not, as the television commercial says: "pay now, or pay [more] later".

When we budget, we always seem to have the funds for the items we put first. Surely the opportunity to save significant numbers of lives, reduce the ultimate cost in dollars as well as pain and suffering, and build the infrastructure for health care for the future must be at, or near, the top of our list. In FY 1994, $200 million will not cover the cost of screening all women in need who qualify for these services, but that funding level will give all 50 States a chance to begin to make the effort.

Thank you for your time and attention, and for considering the lives of millions of women and their loved ones. Please increase the funding for the CDC program and join us in the RACE FOR THE CURE for breast cancer.

REAUTHORIZATION OF THE CDC BREAST AND CERVICAL CANCER PREVENTION PROGRAM

SCOPE OF THE PROBLEM

Breast cancer is the most commonly diagnosed cancer among American women—approximately one in eight women will develop the disease in her lifetime. It is the number one cause of death of women between the ages of 32 and 54. There are 2.6 million women in America today with breast cancer, one million of whom are unaware that they have the disease. In 1993, an estimated 182,000 women will be diagnosed with and 46,000 women will die of breast cancer.

Cervical cancer does not claim as many lives as breast cancer, but it is just as serious, and it remains the third most common cancer of the female genital system. There will be approximately 13,500 new cases and 4,400 deaths from cervical cancer in 1993.

The causes of and prevention strategies for breast and cervical cancer are unknown, and therefore, early detection is crucial to their control. For example, the 5-year survival rate for women with localized breast cancer approaches 100 percent. Cervical cancer is generally believed to be almost fully treatable if the disease is discovered early.

The screening methods for both breast and cervical cancer—mammography and the Pap test—are safe and effective. There is virtually no debate regarding the benefits of breast and cervical cancer screening. An estimated one-third of deaths from breast cancer and almost all deaths from cervical cancer could be prevented if existing screening technology were applied to all women at risk. In addition to the humane aspects of disease prevention and early detection, screening for breast and cervical cancers is also cost-effective. The lifetime cost of treating advanced disease is two to three times that for early disease.

Early detection of breast and cervical cancer, combined with appropriate and timely follow-up, is the most effective method to ensure more effective treatment options, improved survival, and decreased mortality.

Despite the existence of this knowledge for well over a decade, national data for 1990 indicate that only about one-third of women age 40 and older had received a mammogram in the past year, with proportions far lower for older women and women of low income—while Medicare pays for such screening, not all State Medic-

aid programs do so. In addition, despite the benefits of the Pap test, a significant proportion of women are not being screened on a 1regular basis, including women who are past their childbearing years.

Experts agree that a comprehensive, coordinated public health approach is necessary to reduce the number of deaths that result form these cancers. A national infrastructure is essential to support the elements necessary to guarantee all women at risk access to high-quality screening and follow-up services.

THE CDC PROGRAM

On August 10, 1990, the Public Health Service Act was amended to establish a program of grants to states for the increased detection and control of breast and cervical cancer through the Breast and Cervical Cancer Mortality Prevention Act of 1990. This law established the foundation for a comprehensive, national public health approach by authorizing CDC to establish the Annual Breast ad Cervical Cancer Early Detection Program. Through this program, CDC and the States work together to:

—Establish, expand, or improve screening and follow-up services in communities with women at risk.

—Deliver education programs that send the public clear, consistent, and culturally sensitive messages about the lifesaving value of screening. CDC provides intervention assistance and training to participating States to conduct this activity.

—Deliver professional education programs for physicians and other health care professionals to improve skills in education, screening, and diagnostic services.

—Improve quality assurance measures to ensure adherence to standards and guidelines related to screening mammography and cervical cytology.

—Establish surveillance systems that determine where prevention efforts have the most impact, to examine health policy, to evaluate necessary resources, and to monitor program progress.

—Establish State cancer coalitions that include key public, private, and voluntary organizations to marshall resources and establish specific program objectives.

—Stimulate more aggressive action in breast and cervical cancer early detection through a national partnership of Federal, professional, voluntary, and community-based organizations.

PROGRESS TO DATE

Congress appropriated $31 million in 1991 for the program, which provided the following eight State health agencies with cooperative agreement funds to develop comprehensive screening and follow-up programs: California, Colorado, Michigan, Minnesota, New Mexico, South Carolina, Texas, and West Virginia. Thirty-one States had applied for these awards, which ranged between approximately $2.7 and $3 million.

In FY 1992, $50 million was appropriated for the program. This made it possible for CDC to award funds to four additional States for comprehensive programs—Maryland, Missouri, Nebraska, and North Carolina.

In addition, 18 States were awarded funds in FY 1992 to establish capacity-building programs, which develop the infrastructure necessary for having a comprehensive program. The States with capacity-building programs are: Alaska, Arizona, Arkansas, Connecticut, Georgia, Illinois, Indiana, Iowa, Maine, Massachusetts, New York, Ohio, Oregon, Pennsylvania, Rhode Island, Vermont, Washington, and Wisconsin.

In FY 1993, $72.5 million was appropriated for this program, with which CDC expects to fund up to 36 States—18 comprehensive and 18 capacity-building programs. A total of 41 States have expressed interest in participating in the program in FY 1993.

Those States with comprehensive programs expend not less than 60 percent of their grant funds for screening and follow-up services. As of January 15, 1993:

—31,105 eligible women in 10 States had been screened by mammography

—2,774 women had been referred for follow-up

—Breast cancer was diagnosed in 102 women

—53,555 women had been screened by Pap testing

—7,813 women were referred for follow-up

—Cervical intraepithelial neoplasia, an early indicator of cervical cancer, was diagnosed in 3,071 women

—Invasive cervical cancer was diagnosed in 13 women

All State grantees collect and report information on screening location, patient demographic characteristics, screening results, and diagnostic procedures. These data help State health agencies to:

—implement, direct, evaluate, and monitor their screening programs;

—provide State legislators with data on the progress and results of the program; and

—direct and enhance CDC' s efforts with program leadership and technical guidance.

Additionally, each funded State establishes public/private cancer control coalitions which include State and local representatives from professional, voluntary, and community-based organizations.

REAUTHORIZATION ISSUES

Several issues are central to the CDC program and will likely arise during reauthorization. These issues include the following:

—Research and evaluation of the program
—Reimbursement for additional diagnostic services
—Reimbursement costs for treatment
—Expanding the program to additional States
—State matching requirements
—Medicaid coverage of mammography
—Contacting services with for-profit entities
—Providing additional services under the program
—Providing grants to tribes and tribal organizations
—Tracking women served by the program
—Quality assurance provisions
—Impact of health care reform on the program

Prepared by Staff of the Subcommittee on Aging

CANCER FACTS & FIGURES-1993

AMERICAN CANCER SOCIETY

Estimated number of new cancer cases in 1993 by state, total: 1,170,000 (excluding Puerto Rico).*

*Excluding basal and squamous cell skin cancer and carcinoma in situ.
BASED ON RATES FROM NCI SEER PROGRAM (1987-1989).

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Chartered Divisions of the ACS ..... Back Cover

*Table Chart

Sources of Statistics

Incidence

Since there is no nationwide cancer registry, there is no way of knowing exactly how many new cases of cancer are diagnosed each year. The American Cancer Society (ACS) estimates cancer incidence for the upcoming year using the best available data sources at the time.

Estimates of cancer incidence in *Facts and Figures* editions prior to 1974 were based on rates from two state cancer registries, the Connecticut Tumor Registry and the New York State Tumor Registry. The issues from 1974 to 1978 used information from the National Cancer Institute's Third National Cancer Survey (1969-1971) of nine major areas of the United States. In 1973, the NCI began the Surveillance, Epidemiology and End Results (SEER) program to collect ongoing data on cancer incidence and patient survival. The SEER program includes data from nine population-based cancer registries, covering about 10% of the US population. Beginning with the 1979 edition of *Facts and Figures*, estimates of cancer incidence have been based on incidence rates obtained through the SEER program, applied to the US Census estimates of the population for the current year.

It is not appropriate to accurately to evaluate cancer incidence and mortality trends using only ACS estimates of cases and deaths, since these numbers are projected before the year begins, using data that are several years old. The numbers are presented to give the best available measure of the scope of the disease in the US at the time of publication. Comparable incidence rates are available for 1973 through 1989 from the National Cancer Institute's SEER program to evaluate cancer trends.

The estimates of total US cancer cases diagnosed in 1993 are based on age-specific incidence rates from the SEER program for 1983-1989 applied to the 1993 Census population projections. Some adjustment is made for sites with recently increasing or decreasing rates. Estimated new cases by state are calculated according to the distribution of estimated 1993 cancer deaths by state for each primary cancer site.

Mortality

Mortality statistics are derived from underlying cause of death data reported by the Division of Vital Statistics, National Center for Health Statistics, Department of Health and Human Services.

The 1993 estimates of cancer deaths are based on cancer mortality data from 1983 through 1989.

Beginning with the 1981 edition of *Facts and Figures*, age-adjusted mortality rates per 100,000 are standardized to the 1970 census population distribution, rather than the 1940 census population. Age-adjustment or age-standardization is a method used to make valid statistical comparisons among rates by assuming the same age distribution occurs among the different groups being compared.

Death rates by state: Since 1990, actual age-adjusted mortality rates, based on reported deaths in a recent 5-year period, have been presented. For *Facts and Figures* 1969 through 1987 crude death rates were projected for the current year. For *Facts and Figures* 1988 and 1989, age-adjusted death rates were projected. These rates are not comparable and should not be used to evaluate trends over time.

Survival

Cancer survival statistics are usually reported as 5-year relative survival rates. In this edition, we present survival statistics for cases diagnosed in the period 1981-1987, as reported from the SEER program. The relative survival rate is the ratio of the observed survival rate for the patient group to the expected survival rate for persons in the general population similar to the patient group with respect to age, sex, race and calendar year of observation. Because there is a certain lag time required in measuring survival, these rates may not reflect the most recent treatment advances.

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Cancer Basic Facts

What is cancer?

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death.

What causes cancer?

Cancer is caused by both external (chemicals, radiation, and viruses) and internal (hormones, immune conditions, and inherited mutations) factors. Causal factors may act together or in sequence to initiate or promote carcinogenesis. Ten or more years often pass between exposures or mutations and detectable cancer.

Can cancer be prevented?

Yes, about 90% of the 700,000 skin cancers that will be diagnosed in 1993 could have been prevented by protection from the sun's rays. All cancers caused by cigarette smoking and heavy use of alcohol could be prevented completely. The ACS estimates that in 1993, about 160,000 lives will be lost to cancer because of tobacco use. About 17,000 cancer deaths will be related to excessive alcohol use, frequently in combination with cigarette smoking. In addition to prevention, regular screening and self-exams can detect cancers of the breast, tongue, mouth, colon, rectum, cervix, prostate, testis, and melanoma at an early stage, when treatment is more likely to be successful. These sites include nearly half of all new cases. Of these cases, about two-thirds of all patients currently survive five years. With early detection, about 90% would survive. This means that of those persons diagnosed with these cancers in 1993, about 100,000 more would survive if their cancers had been detected in a localized stage and treated promptly.

How is cancer treated?

By surgery, radiation, radioactive substances, chemicals, hormones, and immunotherapy.

Who gets cancer?

Anyone. Since incidence rises with age, most cases affect adults in mid-life or older. Among children ages 1-14, cancer causes more deaths in the US than any other disease. In the 1980s there were over 4.5 million cancer deaths, almost 9 million new cancer cases, and some 12 million people under medical care for cancer.

How many people alive today will get cancer?

About one in three, according to present rates, or about 85 million Americans now living will eventually have cancer.

How many people alive today have ever had cancer?

Over 8 million Americans alive today have a history of cancer, 5 million diagnosed five or more years ago. Most of these 5 million can be considered cured, while others still have evidence of cancer. "Cured" means that a patient has no evidence of disease and has the same life expectancy as a person who never had cancer.

For most forms of cancer, five years without symptoms following treatment is usually accepted as "cured." In some cases, patients can be considered cured in less time, but others have to be observed longer.

How many new cases will there be this year?

In 1993, about 1,170,000 new cancer cases will be diagnosed. This estimate does not include carcinoma in situ and basal and squamous cell skin cancers. The incidence of these skin cancers is estimated to be over 700,000 cases annually.

How many people will die?

This year about 526,000 will die of cancer—about 1,400 people a day. One out of every five deaths in the US is from cancer.

What is the national cancer death rate?

There has been a steady rise in the cancer mortality rate in the US in the last half-century. The age-adjusted rate in 1930 was 143 per 100,000 population. It rose to 152 by 1940, to 163 in 1970, and was 171 in 1989. The major cause of this increase has been lung cancer. Death rates for many major cancer sites have leveled off or declined over the past 50 years (see page 6).

How many people are surviving cancer?

In the early 1900s, few cancer patients had any hope of long-term survival. In the 1930s, less than one in five was alive five years after treatment. In the 1940s, it was one in four, and in the 1960s, it was one in three. About 468,000 Americans, or 4 of 10 patients who get cancer this year, will be alive 5 years after diagnosis. The gain from 1 in 3 in the 1960s to 4 in 10 now represents over 80,000 persons each year.

This 4 in 10, or about 40% is called the "observed" survival rate. When adjusted for normal life expectancy (factors such as dying of heart disease, accidents, and diseases of old age), a "relative" 5-year survival rate of 52% is seen for all cancers. The relative survival rate is commonly used to measure progress in the early detection and treatment of cancer.

Research, Diagnosis, and Treatment

Research into the causes and mechanisms of cancer have created some changes and opportunities in the diagnosis and treatment of the disease. For example, the burgeoning field of cancer genetics is allowing doctors to establish tumor markers to gauge the aggressiveness of disease and use genetic traits to diagnose certain types of cancers.

Some cancers that only a few decades ago had a very poor outlook are often cured today: acute lymphocytic leukemia in children, Hodgkin's disease, Burkitt's lymphoma, Ewing's sarcoma (a form of bone cancer), Wilms' tumor (a kidney cancer in children), rhabdomyosarcoma (a cancer in certain muscle tissue), choriocarcinoma (placental cancer), testicular cancer, and osteogenic (bone) sarcoma. Other cancers, particularly those that have metastasized, have not yet yielded to effective treatment and are the focus of continuing research.

The following developments indicate the directions of current and future research:

• Oncogenes, which play a role in normal cell growth and differentiation, can mutate to cause a loss of control mechanism and allow for the runaway cell growth associated with cancer. The presence of certain oncogenes is being used to predict which tumors are likely to recur after surgery and/or to identify family members at risk.

• Suppressor genes, which exist in normal cells to control cell growth, also play a role in cancer. Some cancers are caused when mutations occur in these genes, allowing uncontrolled cell growth. For example, the p53 suppressor gene frequently is altered in many types of cancer, including breast and lung. In one familial syndrome, where family members have high rates of cancer, about 90% of those who inherit the abnormal p53 gene get cancer by the age of 50. Family members can now be screened for the genetic abnormality before cancer develops.

• Through genetic engineering, researchers may be able to correct impaired immune systems and even modify hereditary susceptibility by transplanting normal copies of genes into cells that have mutated copies of those genes.

• Use of potent growth factors can stimulate normal bone marrow cells to withstand very high doses of chemotherapeutic drugs.

• A genetic fusing of cancer cells with normal cells can produce disease-fighting monoclonal antibodies (specific antibodies tailored to seek out chosen targets on cancer cells). Their potential in the diagnosis and treatment of cancer is under study, and they are showing promise for carrying cancer-killing radiation and drugs to a precise location. Scientists are now developing monoclonal antibodies that have both human and mouse components (originally, these antibodies were all developed in mice) so patients will not develop immune responses to the antibody treatment.

• Researchers are understanding how cancer cells spread to healthy tissues, a process called **metastasis**. Cell mutations can cause increased production of destructive enzymes that allow them to invade surrounding tissues and penetrate blood vessels in order to travel to other parts of the body. A powerful enzyme inhibitor, **TIMP-2** is showing promise for abolishing the metastatic potential of tumor cells. A metastasis suppressor gene, **NM23**, has also been identified.

• New ways have been found to treat early breast and colon cancers postoperatively with drugs. This "adjuvant" treatment may eradicate cancer cells remaining after surgery and increase cure rates.

• Neoadjuvant chemotherapy (giving chemotherapy to shrink the cancer and then removing it surgically) has been successful against various types of cancers. This is one of the most promising of new treatment approaches.

• Understanding the causes of pain in cancer patients has increased the options for controlling pain. Regular use of orally administered pain medicines, infusions or injections of analgesics, and procedures to interrupt pain pathways are among the effective approaches available for the majority of patients with pain from cancer.

• Researchers are examining synthetic retinoids (cousins of vitamin A) and other substances to see if recurrences of certain cancers can be prevented and if these agents can reduce cancer in high-risk groups. The cancer prevention capabilities of carotenoids, vitamin A derivatives, are also being researched.

• In clinical trials, taxol, an agent obtained currently from the bark of Pacific yew trees, has been effective in treating ovarian cancer. Research efforts are underway to synthesize this scarce drug in the laboratory and the synthesized taxol will soon become available for critical research to test its efficacy.

• New approaches to drug therapy use combinations of chemotherapeutic drugs, or chemotherapy plus surgery or radiation. New classes of agents are being tested for their effectiveness in treating patients whose disease is resistant to drug therapies now in use. Understanding the basis of drug resistance and developing counterattacks are major areas of research today.

• Many patients with primary bone cancer now are treated successfully by removing and replacing a section of bone rather than by amputating the leg or arm. Drugs

and radiation therapy are being used effectively after bone cancer surgery, resulting in dramatic improvement in survival.

• New high-technology diagnostic imaging techniques have replaced exploratory surgery for some cancer patients. Magnetic resonance imaging (MRI) is one example of such technology. In MRI, a huge electromagnet is used to detect hidden tumors by mapping the vibrations of the various atoms in the body on a computer screen. Computerized tomography (CT) scanning uses x-rays to examine parts of the body. In both of these painless, noninvasive procedures, cross-section pictures can show a tumor's shape and location more accurately than is possible with conventional x-ray techniques. For patients undergoing radiation therapy, CT scanning may enable the therapist to pinpoint the tumor more precisely, and thus provide more accurate radiation dosage while sparing normal tissue. Positron emission tomography (PET) is another imaging technique. One of the advances in the area of imaging combines two or three different types of images (e.g., MRI and PET) in a computer to create a three-dimensional picture that can be rotated on the screen. This technology is currently used in some medical centers to help plan for surgery and radiation therapy in areas such as the brain.

• Immunotherapy holds the hope of enhancing the body's own disease-fighting systems to control cancer. Interferon (a naturally occurring body protein capable of killing cancer cells or stopping their growth), interleukin-2 (a growth factor that greatly stimulates cells of the immune system to directly fight cancer), and other biologic response modifiers are under study. Recently, interferon was made available to all doctors as the treatment for hairy cell leukemia, a rare blood cancer of older Americans. Interleukin-2 is under very active research in the treatment of kidney cancer and melanoma. Gene therapy is the newest approach to stimulating immune cells to fight cancer.

• Many cancers are caused by a two-stage process through exposure to substances known as initiators and promoters. Research scientists are exploring ways of interrupting this process to prevent the development of cancer.

• Ongoing research into new drug development will result in compounds that are less toxic to normal cells and more potent against tumor cells. New drugs will also allow physicians to circumvent the problem of drug resistance that many cancer cells develop. Along that same line of research, genes responsible for cancer cell resistance to chemotherapy have recently been discovered.

• New technologies have made it possible to use bone marrow transplantation as an important treatment option in select patients with leukemia, lymphoma, or breast cancer. Bone marrow transplantation for other cancers is under study. Because disruption of bone marrow function is a side effect of some cancer treatments, researchers are evaluating autologous bone marrow transplants, in which a portion of the patient's own marrow is removed before treatment, saved, and later restored. This procedure eliminates the problems of matching a donor with the recipient patient, and may make it possible for the patient to tolerate larger doses of anticancer drugs or radiation therapy.

• With medical progress producing longer survival periods for many cancer patients, clinical concerns are expanding to include not only patients' physical well-being, but also their psychosocial needs. The response of both patient and family to the disease, the patient's sexual concerns, employment and insurance needs, and ways to provide psychosocial support have emerged as important areas of research and clinical care.

• Improvements in cancer treatment have made possible more conservative management of some early cancers. In early cancer of the larynx, many patients are now able to retain the larynx and voice; in colorectal cancer, fewer permanent colostomies are needed; in many cases, the surgery for breast cancer is often more limited; and special nerve-sparing surgery now commonly used for prostate cancer could enable men to maintain normal penile function.

• Prostatic ultrasound (a rectal probe using ultrasonic waves to produce an image of the prostate) is currently being investigated as a potential means to increase the early detection of occult (not clinically suspected) prostate cancer. Recently, prostatic ultrasound has been combined with a blood test for prostate-specific antigen to aid in early detection of prostate cancer.

• A large clinical trial is underway to evaluate the usefulness of an estrogen-blocking drug called tamoxifen. Commonly used to treat women when they have breast cancer, this large study hopes to see if tamoxifen can also be used to prevent breast cancer in women who are at high risk.

• Psychosocial and behavioral research is showing much promise as evidence mounts that lifestyle (tobacco, diet) and environmental factors influence a person's general health and chances of developing cancer, as well as the mental ability to cope with cancer if it occurs. Research on behavioral modification is having a significant impact on symptoms of cancer and its treatment, such as pain, nausea, and vomiting. Other research deals with stress during treatment and during recovery after surgery or radiation treatment. A number of investigations concentrate on breast cancer, specifically on how women can be motivated to make use of mammography screening, and how to adjust to surgery, if such intervention becomes necessary.

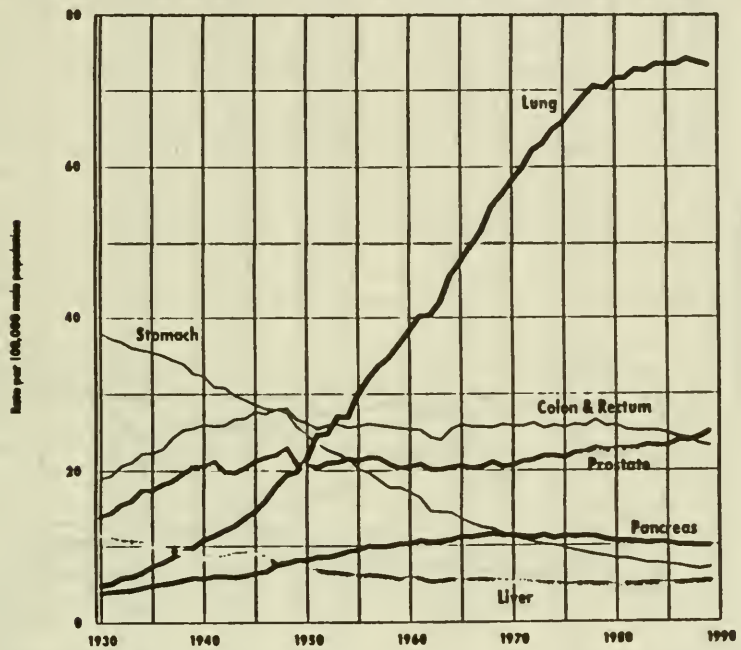
Costs of Cancer

The financial costs of cancer are great both for the individual and for society as a whole. The National Cancer Institute estimates overall costs for cancer at $104 billion for 1990; $35 billion for direct medical costs, $12 billion for morbidity costs (cost of lost productivity), and $57 billion for mortality costs. Earlier figures showed that cancer accounts for 10% of the total cost of disease in the US and that its share of the total cost of premature death was about 18% of all causes of death in 1985.

The cost of cancer screenings, including mammograms, Pap smears, and colorectal exams adds another $3 to $4 billion to overall cancer costs.

Individual medical costs may be covered by private insurance companies or public health insurance programs

Cancer Death Rates by Site, Males, United States, 1930-89



Rates are adjusted to the 1970 US census population

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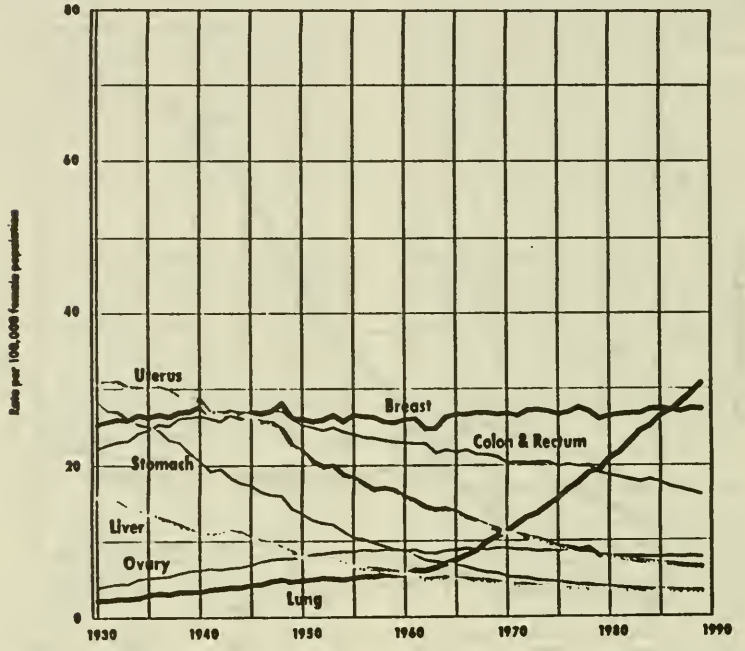
such as Medicare, Medicaid, and Veterans Affairs. Most of the non-elderly population receive their primary coverage through employment-based group insurance. Medicare covers medical costs for those 65 and over and the disabled, about 34 million persons in 1989. Medicaid serves the poor, covering about 24 million people. About 33 million people, or about 14% of the population, had no health care coverage in 1989.

In 1989 and 1990, Congress passed legislation mandating Medicare coverage for cervical and breast cancer screening, respectively. For women over age 65, Medicare currently covers a Pap smear once every three years and a mammogram every two years. Although this policy does not strictly conform to ACS screening recommendations (see page 21), it does begin to address the benefits of early detection.

Cancer Death Rates by Site, Females, United States, 1930-89



Rates are adjusted to the 1970 US census population.

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30-Year Trends In Cancer Death Rates* per 100,000 Population, 1957-59 to 1987-89

Sites	Sex	1957-1959	1987-1989	Percent Changes	Number of Deaths 1959	Number of Deaths 1989
All Sites	Male	180.4	216.2	20%	139,078	263,309
	Female	138.2	139.8	†	120,969	232,843
Oral	Male	6.1	4.6	-24%	4,710	5,340
	Female	1.5	1.7	11%	1,343	2,764
Esophagus	Male	4.8	5.8	21%	3,722	7,154
	Female	1.2	1.5	25%	1,097	2,483
Stomach	Male	18.8	6.9	-62%	13,271	8,520
	Female	9.3	3.1	-66%	7,753	5,666
Colon & rectum	Male	25.2	23.6	-6%	18,741	28,248
	Female	23.1	16.4	-29%	19,748	29,134
Colon	Male	17.0	20.2	19%	12,633	24,152
	Female	17.5	14.3	-18%	15,116	25,581
Rectum	Male	8.3	3.5	-58%	6,108	4,096
	Female	5.6	2.1	-63%	4,632	3,553
Liver‡	Male	5.8	5.1	-12%	4,292	6,383
	Female	6.1	3.2	-48%	5,216	5,636
Pancreas	Male	10.0	9.8	†	7,854	11,965
	Female	6.2	7.1	16%	5,462	12,578
Larynx	Male	2.6	2.5	†	2,021	2,961
	Female	0.3	0.5	87%	238	768
Lung	Male	34.9	73.7	111%	29,335	89,052
	Female	5.4	29.4	440%	4,967	48,098
Melanoma of skin	Male	1.3	3.0	122%	1,098	3,736
	Female	1.0	1.5	50%	954	2,425
Other skin	Male	1.7	1.3	-25%	1,214	1,532
	Female	0.9	0.4	-56%	680	657
Breast	Male	0.3	0.2	-22%	214	301
	Female	25.8	27.2	6%	22,871	42,837
Cervix uteri	Female	9.6	3.0	-69%	8,383	4,487
Other uterus	Female	7.2	3.5	-52%	6,005	5,867
Ovary	Female	8.8	7.8	-11%	7,901	12,431
Prostate	Male	20.9	24.4	17%	14,037	30,520
Bladder	Male	7.2	5.6	-22%	5,288	6,843
	Female	2.8	1.7	-40%	2,352	3,278
Kidney	Male	3.7	5.0	35%	3,065	6,133
	Female	2.0	2.4	20%	1,788	3,979
Brain	Male	4.0	5.0	25%	3,593	6,046
	Female	2.7	3.4	26%	2,439	5,084
Non-Hodgkin's lymphoma	Male	4.7	7.4	56%	3,842	9,420
	Female	3.1	4.9	57%	2,837	8,777
Hodgkin's disease	Male	2.3	0.8	-66%	1,920	1,007
	Female	1.3	0.5	-65%	1,131	714
Multiple myeloma	Male	1.9	3.6	91%	1,515	4,335
	Female	1.3	2.4	80%	1,226	4,252
Leukemia	Male	8.8	8.1	-8%	7,123	10,039
	Female	5.7	4.8	-16%	5,147	8,207

*Adjusted to the age distribution of the 1970 US Census Population. †Percent change is less than ±1%. ‡Primary and non specified.

Note: Even though death rates declined or remained stable, the number of deaths increased because the population has become larger and older. The US population increased 40% from 1959 to 1989.

Estimated New Cancer Cases and Deaths, United States—1993*

	Estimated New Cases			Estimated Deaths		
	Both Sexes	Male	Female	Both Sexes	Male	Female
All sites	1,170,000	600,000	570,000	526,000	277,000	249,000
Buccal cavity & pharynx (Oral)	29,800	20,300	9,500	7,700	4,975	2,725
Lip	3,500	3,000	500	100	75	25
Tongue	5,900	3,800	2,100	1,750	1,100	650
Mouth	11,200	6,800	4,400	2,050	1,200	850
Pharynx	9,200	6,700	2,500	3,800	2,600	1,200
Digestive organs	236,900	125,200	111,700	120,325	64,350	55,975
Esophagus	11,300	8,100	3,200	10,200	7,600	2,600
Stomach	24,000	14,800	9,200	13,600	8,200	5,400
Small intestine	3,600	2,000	1,600	925	500	425
Large intestine (Colon-Rectum)	109,000	53,000	56,000	50,000	25,000	25,000
Rectum	43,000	24,000	19,000	7,000	3,800	3,200
Liver and biliary passages	15,800	8,500	7,300	12,600	6,800	5,800
Pancreas	27,700	13,500	14,200	25,000	12,000	13,000
Other and unspecified digestive	2,500	1,300	1,200	1,000	450	550
Respiratory system	187,100	113,000	74,100	154,200	96,900	57,300
Larynx	12,600	10,000	2,600	3,800	3,000	800
Lung	170,000	100,000	70,000	149,000	93,000	56,000
Other & unspecified respiratory	4,500	3,000	1,500	1,400	900	500
Bone	2,000	1,100	900	1,050	600	450
Connective tissue	6,000	3,300	2,700	3,100	1,500	1,600
Melanoma of skin	32,000	17,000	15,000	6,800	4,200	2,600
Breast	183,000	1,000	182,000	46,300	300	46,000
Genital organs	244,400	172,900	71,500	59,950	35,550	24,400
Cervix uteri (Uterus)	13,500	—	13,500	4,400	—	4,400
Corpus & unspecified (Uterus)	31,000	—	31,000	5,700	—	5,700
Ovary	22,000	—	22,000	13,300	—	13,300
Other & unspecified genital, female	5,000	—	5,000	1,000	—	1,000
Prostate	165,000	165,000	—	35,000	35,000	—
Testis	6,600	6,600	—	350	350	—
Other & unspecified genital, male	1,300	1,300	—	200	200	—
Urinary organs	79,500	55,800	23,700	20,800	13,000	7,800
Bladder	52,300	39,000	13,300	9,900	6,500	3,400
Kidney & other urinary	27,200	16,800	10,400	10,900	6,500	4,400
Eye	1,750	950	800	250	125	125
Brain & central nervous system	17,500	9,600	7,900	12,100	6,600	5,500
Endocrine glands	14,050	4,150	9,900	1,725	800	925
Thyroid	12,700	3,400	9,300	1,050	450	600
Other endocrine	1,350	750	600	675	350	325
Leukemia	29,300	16,700	12,600	18,600	10,100	8,500
Lymphocytic leukemia	12,600	7,500	5,100	5,400	3,100	2,300
Granulocytic leukemia	11,700	6,400	5,300	7,300	3,900	3,400
Other & unspecified leukemia	5,000	2,800	2,200	5,900	3,100	2,800
Other blood & lymph tissues	63,700	35,000	28,700	31,400	16,300	15,100
Hodgkin's disease	7,900	4,500	3,400	1,500	900	600
Non-Hodgkin's lymphoma	43,000	24,000	19,000	20,500	10,600	9,900
Multiple myeloma	12,800	6,500	6,300	9,400	4,800	4,600
All other & unspecified sites	43,000	24,000	19,000	41,700	21,700	20,000

*Carcinoma in situ and basal and squamous cell skin cancers are not included in totals. Carcinoma in situ of the uterine cervix accounts for about 55,000 new cases annually, carcinoma in situ of the female breast accounts for about 25,000 new cases annually, and melanoma carcinoma in situ accounts for about 8,000 new cases annually. Overall, about 100,000 new cases of carcinoma in situ of all sites of cancer are diagnosed each year.

Basal cell and squamous cell skin cancers account for more than 700,000 new cases annually. About 2,300 nonmelanoma skin cancer deaths will occur in 1993.

Incidence estimates are based on rates from NCI SEER program 1987-89.

Estimated New Cancer Cases, by State—1993

State	All Sites*	Female Breast	Colon & Rectum	Lung	Oral	Uterus	Prostate	Skin Melanoma	Pancreas	Leukemia
Alabama	20,800	2,700	2,200	3,700	600	900	2,800	350	475	450
Alaska	1,700	200	125	250	50	50	125	50	30	40
Arizona	16,500	2,400	2,000	2,500	350	500	2,400	550	375	475
Arkansas	13,200	1,800	1,700	2,300	250	500	2,000	325	325	350
California	120,000	18,500	14,500	17,000	3,200	4,600	16,000	3,800	3,000	3,100
Colorado	11,300	1,800	1,500	1,400	375	350	1,900	450	300	300
Connecticut	16,200	2,600	2,400	2,200	425	550	1,900	400	400	400
Delaware	3,500	600	500	550	125	125	500	100	70	80
Dist. of Columbia	4,000	600	550	500	150	150	800	70	90	90
Florida	78,000	11,300	10,300	12,700	2,600	2,600	12,500	2,400	1,900	1,900
Georgia	27,500	4,400	3,100	4,200	950	1,000	4,000	850	650	650
Hawaii	3,900	425	600	500	100	125	550	70	100	75
Idaho	4,000	550	500	550	100	175	700	125	100	125
Illinois	55,000	8,700	7,600	7,700	1,300	2,200	7,400	1,300	1,300	1,400
Indiana	26,800	4,300	3,400	4,200	550	1,000	3,500	600	550	650
Iowa	13,900	2,300	2,100	2,000	350	400	2,300	450	325	375
Kansas	11,600	1,900	1,700	1,700	350	450	1,600	350	275	350
Kentucky	19,300	3,600	3,300	3,400	375	750	2,200	500	375	375
Louisiana	19,900	2,800	2,300	3,200	550	850	2,600	400	550	450
Maine	6,700	900	900	950	175	225	950	200	175	150
Maryland	22,500	3,400	2,800	3,300	550	800	3,200	600	550	500
Massachusetts	30,500	5,100	4,400	4,100	950	1,000	3,900	900	700	700
Michigan	47,000	6,800	5,400	6,000	1,000	1,700	6,100	850	950	1,100
Minnesota	19,000	3,100	2,600	2,300	375	700	3,400	500	500	550
Mississippi	12,900	1,700	1,500	2,100	325	550	1,900	275	325	300
Missouri	26,500	4,100	3,700	4,100	650	950	3,600	650	550	650
Montana	3,800	500	550	500	125	125	700	125	90	80
Nebraska	7,500	1,300	950	1,100	150	250	1,200	275	175	175
Nevada	5,600	800	600	1,000	100	200	700	125	150	150
New Hampshire	5,700	900	700	750	150	225	800	125	125	100
New Jersey	41,000	6,900	5,700	5,600	1,100	1,600	5,600	1,200	900	900
New Mexico	5,600	900	700	650	125	200	800	150	150	175
New York	88,000	15,600	13,000	11,400	2,400	3,500	11,000	2,400	2,200	3,000
North Carolina	32,000	5,000	4,000	4,800	900	1,300	5,200	1,000	750	800
North Dakota	3,100	425	425	350	60	100	700	70	80	100
Ohio	53,000	8,900	7,300	8,000	1,200	2,200	6,900	1,300	1,200	1,400
Oklahoma	15,300	2,100	1,800	2,400	400	700	2,100	400	325	400
Oregon	14,100	2,000	1,700	2,100	350	550	2,200	400	350	375
Pennsylvania	67,000	10,700	9,600	9,300	1,900	2,700	9,700	1,700	1,500	1,700
Rhode Island	5,500	950	800	750	175	200	800	125	125	100
South Carolina	15,500	2,300	1,800	2,400	600	700	2,200	425	375	400
South Dakota	3,300	550	450	450	50	100	600	75	90	90
Tennessee	24,600	3,500	3,200	4,100	500	1,000	3,300	700	600	600
Texas	63,000	9,000	7,200	9,300	1,500	2,300	7,900	1,600	1,500	1,800
Utah	4,500	750	550	375	75	250	900	150	125	150
Vermont	2,600	450	300	350	40	75	450	75	60	70
Virginia	27,000	4,400	3,200	4,200	650	1,000	4,000	750	600	600
Washington	21,000	3,300	2,600	3,100	500	600	3,300	600	475	550
West Virginia	10,600	1,600	1,300	1,800	250	400	1,200	225	225	275
Wisconsin	23,000	3,600	3,100	2,800	400	850	3,800	550	550	650
Wyoming	1,900	300	200	225	25	75	225	40	40	75
United States	1,170,000	182,000	152,000	170,000	29,800	44,500	165,000	32,000	27,700	29,300
Puerto Rico	8,700	1,200	1,100	850	425	425	1,300	60	200	250

*Does not include carcinoma in situ or basal and squamous cell skin cancers

These estimates are offered as a rough guide and should not be regarded as definitive. They are calculated according to the distribution of estimated 1993 cancer deaths by state.

Cancer Mortality by State—1993

State	Reported Death Rate per 100,000*	Estimated Number of Deaths									
		All Sites	Female Breast	Colon & Rectum	Lung	Oral	Uterus	Prostate	Skin Melanoma	Pancreas	Leukemia
Alabama	179	9,300	700	950	2,800	150	725	600	125	425	300
Alaska	165	500	50	50	175	10	10	25	10	25	20
Arizona	155	7,500	600	750	2,200	80	100	500	125	350	300
Arkansas	173	5,900	450	600	2,000	60	125	400	70	300	225
California	168	52,000	4,500	5,400	14,200	850	1,000	3,500	850	2,700	1,900
Colorado	140	5,000	450	550	1,200	70	80	400	100	275	175
Connecticut	172	7,300	650	900	1,900	100	125	400	80	350	250
Delaware	195	1,600	175	175	475	40	30	100	25	60	50
Dist. of Columbia	228	1,800	150	225	450	50	60	175	20	80	60
Florida	145	36,000	2,900	3,800	11,000	850	600	2,700	500	1,700	1,200
Georgia	176	12,400	1,100	1,100	2,700	225	225	850	175	550	425
Hawaii	139	1,700	100	200	425	25	30	100	20	90	50
Idaho	146	1,800	150	200	450	20	40	150	20	100	80
Illinois	179	24,400	2,200	2,900	6,800	350	500	1,600	250	1,200	850
Indiana	179	12,100	1,000	1,300	3,700	125	225	750	125	500	425
Iowa	161	6,300	600	800	1,700	80	90	475	100	300	250
Kansas	155	5,200	475	600	1,500	70	100	325	70	250	225
Kentucky	185	8,700	650	900	3,000	100	175	475	100	350	250
Louisiana	187	9,000	700	850	2,800	150	700	550	80	500	300
Maine	185	3,000	225	325	900	50	50	200	40	150	90
Maryland	198	10,100	850	1,100	2,900	150	175	650	125	475	325
Massachusetts	179	13,700	1,300	1,700	3,700	250	225	800	200	650	450
Michigan	177	19,100	1,700	2,000	5,300	275	400	1,300	175	900	700
Minnesota	156	8,500	800	1,000	1,900	90	150	700	100	475	350
Mississippi	174	5,800	475	550	1,800	90	125	400	60	300	200
Missouri	173	11,900	1,000	1,200	3,700	125	225	750	125	500	425
Montana	157	1,700	125	200	450	30	30	150	30	75	50
Nebraska	159	3,400	325	350	900	60	80	250	60	150	125
Nevada	184	2,500	200	225	650	20	50	150	25	125	80
New Hampshire	183	2,400	225	250	650	40	60	175	30	100	60
New Jersey	185	18,300	1,800	2,700	4,800	275	375	1,100	250	800	600
New Mexico	144	2,500	225	250	600	50	50	175	30	125	100
New York	177	39,500	4,000	4,800	10,000	650	850	2,400	500	1,900	1,300
North Carolina	171	14,600	1,300	1,500	4,400	225	300	1,000	225	700	500
North Dakota	151	1,400	100	150	300	20	25	150	10	70	70
Ohio	181	24,000	2,200	2,700	7,000	300	575	1,500	275	1,100	900
Oklahoma	164	6,900	550	700	2,100	100	150	450	90	275	250
Oregon	168	6,300	500	650	1,900	90	125	450	90	300	250
Pennsylvania	180	30,300	2,700	3,600	8,200	375	600	2,100	375	1,400	1,100
Rhode Island	187	2,500	250	300	700	40	40	150	25	100	75
South Carolina	173	7,000	550	700	2,200	150	150	475	80	350	250
South Dakota	153	1,500	150	175	375	20	25	125	10	70	60
Tennessee	176	11,000	900	1,200	3,600	125	225	700	150	550	375
Texas	158	29,200	2,300	2,800	8,300	400	500	1,600	325	1,400	1,100
Utah	121	2,000	200	200	325	20	50	200	40	100	80
Vermont	174	1,100	125	100	275	10	20	100	20	50	50
Virginia	180	12,200	1,100	1,200	3,600	150	275	850	150	550	400
Washington	165	9,300	850	950	2,700	125	175	700	125	425	350
West Virginia	178	4,700	350	500	1,500	70	80	300	70	200	150
Wisconsin	164	10,300	900	1,200	2,600	150	200	800	125	500	400
Wyoming	147	800	75	75	200	10	20	75	10	30	40
United States	172	526,000	46,000	57,000	149,000	7,700	10,100	35,000	6,900	25,000	18,600
Puerto Rico	130	6,200	375	425	800	150	125	400	20	175	175

*Average annual mortality rate for 1985-1989, adjusted to the age distribution of the 1970 US Census Population.

Selected Cancers

Lung Cancer

Incidence: An estimated 170,000 new cases in 1993. The incidence rate, which had been increasing steadily in men and women for several decades, has declined in men, from a high of 87 per 100,000 in 1984 to 80.1 in 1989. The incidence rate in women continues to increase to 39.3 per 100,000 in 1989.

Mortality: An estimated 149,000 deaths in 1993. Since 1987, more women have died of lung cancer than breast cancer, which, for over 40 years, was the major cause of cancer death in women.

Warning Signals: Persistent cough, sputum streaked with blood, chest pain, recurring pneumonia or bronchitis.

Risk Factors: Cigarette smoking; exposure to certain industrial substances, such as arsenic, certain organic chemicals and asbestos, particularly for persons who smoke; radiation exposure from occupational, medical, and environmental sources. Residential radon exposure may increase risk, especially in cigarette smokers. Exposure to sidestream cigarette smoke increases the risk for nonsmokers.

Early Detection: Because symptoms often don't appear until the disease is in advanced stages, early detection is very difficult. In smokers who stop smoking at the time of early precancerous cellular changes, damaged bronchial lining tissues often return to normal. Smokers who persist in smoking may form abnormal cell growth patterns that lead to cancer. Chest x-ray, analysis of the types of cells contained in sputum, and fiberoptic examination of the bronchial passages assist diagnosis.

Treatment: Determined by the type and stage of the cancer. Options include surgery, radiation therapy, and chemotherapy. For many localized cancers, surgery is usually the treatment of choice. Because the disease has usually spread by the time it is discovered, radiation therapy and chemotherapy are often needed in combination with surgery. In small cell cancer, chemotherapy alone or combined with radiation has replaced surgery as the treatment of choice; on this regimen, a large percentage of patients experience remission, which in some cases is long-lasting.

Survival: The 5-year relative survival rate is only 13% in all patients, regardless of stage at diagnosis. The rate is 46% for cases detected when the disease is still localized, but only 16% of lung cancers are discovered that early.

Colon and Rectum Cancer

Incidence: An estimated 152,000 new cases in 1993, including 109,000 of colon cancer and 43,000 of rectum cancer. Incidence rates appear to be declining for all groups except for black men.

Mortality: An estimated 57,000 deaths (50,000 from colon cancer, 7,000 from rectum cancer) in 1993. Mortality from colorectal cancer has fallen 29% for women and 6% for men over the last 30 years.

Warning Signals: Rectal bleeding, blood in the stool, change in bowel habits.

Risk Factors: Personal or family history of cancer or polyps of the colon or rectum; inflammatory bowel disease. High-fat and/or low-fiber diet may be associated with increased risk.

Early Detection: Digital rectal examination, stool blood test, and proctosigmoidoscopy are recommended by the American Cancer Society to detect colon or rectum cancer in asymptomatic patients.

Digital rectal examination is performed by a physician during an office visit. The American Cancer Society recommends that this examination be performed annually after age 40.

The stool blood test is a simple method to test feces for hidden blood. The specimen is obtained by the patient at home and returned to the physician's office, a hospital, or a clinic for analysis. The Society recommends annual testing after age 50.

In proctosigmoidoscopy, the physician uses a hollow lighted tube to inspect the rectum and lower colon. To detect cancers higher in the colon, longer, flexible instruments are being used, as well as a rigid scope. The American Cancer Society recommends the use of this examination every 3 to 5 years after age 50.

If any of these tests reveal possible problems, more extensive studies, such as colonoscopy (examination of the entire colon) and barium enema (an x-ray procedure in which the intestines are viewed), may be needed.

Treatment: Surgery, at times combined with radiation, is the most effective method of treating colorectal cancer. The role of chemotherapy in treating advanced cases is under study. Combinations of chemotherapy and immunologic agents have recently been described as beneficial in postoperative patients with cancerous lymph nodes.

Colostomy (creation of an abdominal opening for elimination of body wastes) is seldom needed for colon cancer and is infrequently required for rectal cancer. The American Cancer Society has a patient assistance program

for those who do have permanent colostomies (see p. 27).

Survival: When colorectal cancer is detected in an early, localized stage, the 5-year survival rates are 91% for colon cancer and 85% for rectal cancer. After the cancer has spread regionally, to involve adjacent organs or lymph nodes, the survival rates drop to 60% and 51%, respectively. Survival rates for persons with distant metastases are less than 7%.

Breast Cancer

Incidence: An estimated 182,000 new cases among women in the United States during 1993. Approximately one of every nine women will develop breast cancer by age 85. About 1,000 new cases of breast cancer will be diagnosed in men in 1993. Breast cancer incidence rates for women increased about 2% a year since the early 1970s, but have leveled off since 1987 at about 107 per 100,000. Some of the recent rise in rates is believed to be due to marked increases in mammography utilization, allowing the detection of early stage breast cancers, frequently before they would become clinically apparent. Other reasons for a long-term increase in breast cancer are not yet understood.

Mortality: An estimated 46,300 deaths (46,000 women, 300 men) in 1993; in women, the second major cause of cancer death. Although incidence rates are increasing, early detection and improved treatment have kept mortality rates fairly stable over the past 50 years.

Warning Signals: Breast changes that persist, such as a lump, thickening, swelling, dimpling, skin irritation, distortion, retraction, scaliness, pain, or tenderness of the nipple.

Risk Factors: Over age 40, increases with age; personal or family history of breast cancer; early age at menarche, late age at menopause, never had children or late age at first live birth, and higher education and socioeconomic status. International variability in cancer incidence rates correlate with variations in diet, especially fat intake, although a causal role for dietary factors has not been firmly established. Breast cancer risk factors appear to be more useful in providing clues to the development of cancer than in identifying prevention strategies. Since adult women may not be able to alter their personal risk factors in any practical sense, the best opportunity for reducing mortality is through early detection. Many women will have one or more risk factors for breast cancer. However, most risks are at such a low level that they only partly explain the high frequency of the disease in the population.

Early Detection: The Society recommends that women have a screening mammogram by age 40; women 40 to 49 should have a mammogram every 1-2 years; asymptomatic women age 50 and over should have a mammogram every year. In addition, a clinical physical examination of the breast is recommended every three years for women 20 to 40, and every year for those over 40. The Society also recommends monthly breast self-examination as a routine good health habit for women 20 years or older. Most breast lumps are not cancer, but only a physician can make a diagnosis.

Besides its effectiveness in screening asymptomatic women, mammography is recognized as a valuable diagnostic technique for women who have findings suggestive of breast cancer. Once a breast lump is found, mammography can help determine if there are other lesions too small to be felt, in the same or opposite breast. Since a small percentage of breast cancers may not be seen on a mammogram, all suspicious lumps should be biopsied for a definitive diagnosis, even when current or recent mammography findings are described as normal.

Treatment: Taking into account the medical situation and the patient's preferences, treatment may require lumpectomy (local removal of the tumor), mastectomy (surgical removal of the breast), radiation therapy, chemotherapy, or hormone manipulation therapy. Often, two or more methods are used in combination.

Patients should discuss with their physicians possible options for the best management of their breast cancer.

New techniques in recent years have made breast reconstruction possible after mastectomy, and the cosmetic results usually are good. Reconstruction has become an important part of treatment and rehabilitation.

Survival: The 5-year survival rate for localized breast cancer has risen from 78% in the 1940s to 93% today. If the breast cancer is in situ (not invasive), the survival rate approaches 100%. If the cancer has spread regionally, however, the survival rate is 71%, for persons with distant metastases, the survival rate is 18%.

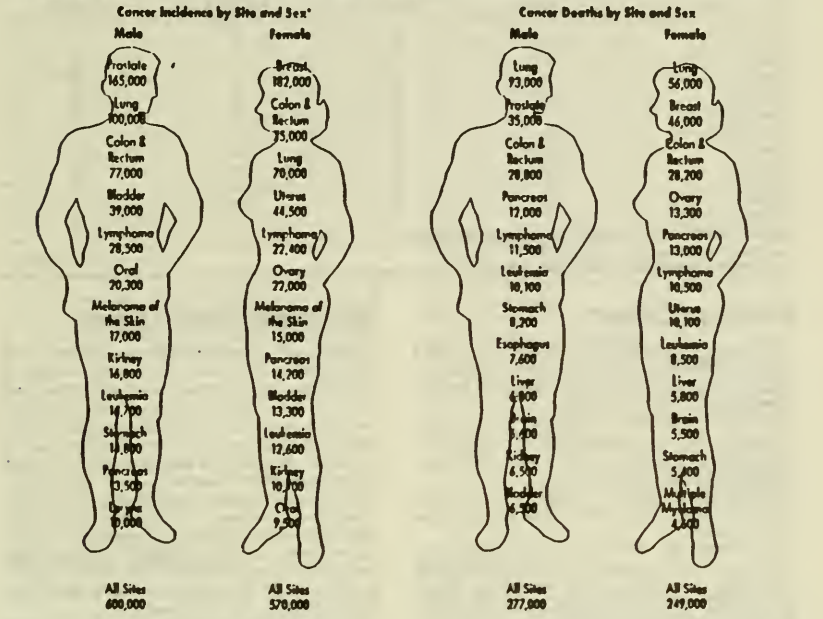
Prostate Cancer

Incidence: An estimated 165,000 new cases in the United States during 1993. Approximately one of every 10 men will develop prostate cancer by age 85. Prostate cancer incidence rates are 40% higher for black men than white men. Since the 1980s prostate cancer incidence rates have risen 4% a year largely due to improved detection. Further increased incidence is expected with widespread use of serum screening tests.

Mortality: An estimated 35,000 deaths in 1993, the second leading cause of cancer deaths in men.

Warning Signals: Weak or interrupted urine flow; inability to urinate, or difficulty starting or stopping the urine flow; the need to urinate frequently, especially at night; blood in the urine; pain or burning on urination; continuing pain in lower back, pelvis, or upper thighs. Most of these symptoms are nonspecific and may be similar

Leading Sites of Cancer Incidence and Deaths—1993 Estimates



*Excluding basal and squamous cell skin cancer and carcinoma in situ. Available as reproduction sheet (2005.93)

to those caused by benign conditions such as infection or prostate enlargement.

Risk Factors: Incidence increases with age; over 80% of all prostate cancers are diagnosed in men over age 65. The disease is more common in northwestern Europe and North America. It is rare in the Near East, Africa, Central America, and South America. For reasons not currently known, black Americans have the highest incidence rate in the world. There is some familial association, but it is unclear whether this is due to genetic or environmental factors. International studies suggest that dietary fat may be a factor.

Early Detection: Every man 40 and over should have a digital rectal examination as part of his regular annual physical checkup. In addition the ACS recommends that men 50 and over have annual prostate-specific antigen blood testing. If either result is suspicious, further evaluation in the form of transrectal ultrasound should be performed.

Treatment: Surgery, radiation, and/or hormones and anticancer drugs, are treatment options. Hormone treatment and anticancer drugs may control prostate cancer for long periods by shrinking the size of the tumor, thus relieving pain.

Survival: Fifty-eight percent of all prostate cancers are discovered while still localized; the 5-year relative survival rate for patients whose tumors are diagnosed at this stage is 91%. Survival rates for all stages combined have steadily improved, and in the past 30 years have increased from 50% to 76%.

Five-Year Survival Rates by Stage at Diagnosis*

Site	All Stages %	Local %	Regional %	Distant %
Oral	52	76	41	19
Colon-rectum	57	89	58	6
Pancreas	3	8	4	1
Lung	13	46	13	1
Melanoma	83	91	54	13
Female breast	78	93	71	16
Cervix uteri	66	89	52	14
Corpus uteri	83	94	68	26
Ovary	39	89	37	18
Prostate	76	91	80	28
Bladder	78	90	46	9
Kidney	55	85	56	9

*Adjusted for normal life expectancy. This chart based on cases diagnosed in 1983-87, followed through 1989.

Source: Cancer Statistics Branch, National Cancer Institute

Available on reproduction sheet (5005.93)

Pancreas Cancer

Incidence: An estimated 27,700 new cases in the United States in 1993. The disease is 30% more common in men, and occurs approximately 40% more frequently in black Americans than in white Americans.

Mortality: An estimated 25,000 deaths in 1993. Pancreatic cancer incidence and mortality rates have been fairly stable since the early 1970s, except among black women, whose rates have increased slightly.

Warning Signals: Cancer of the pancreas is a "silent" disease, one that occurs without symptoms until it is in advanced stages.

Risk Factors: Very little is known about what causes the disease or how to prevent it. Risk increases after age 50, with the most cases occurring between ages 65 and 79. Smoking is a risk factor; incidence is more than twice as high for smokers as nonsmokers. Some studies have suggested associations with chronic pancreatitis, diabetes, or cirrhosis, but these findings have not been confirmed. In countries where the diet is high in fat, pancreatic cancer rates are higher.

Early Detection: At present, only a biopsy yields a certain diagnosis, and because of the "silent" course of the disease, the need for biopsy is likely to be obvious only after the disease has advanced. Researchers are focusing on ways to diagnose pancreatic cancer before symptoms occur. Ultrasound imaging and computerized tomography (CT) scans are being tried.

Treatment: Surgery, radiation therapy, and anticancer drugs are treatment options, but have had little influence on the outcome. Diagnosis is usually so late that none of these is used.

Survival: Only 3% of patients live more than 5 years after diagnosis.

Uterus and Cervix Cancer

Incidence: An estimated 44,500 new invasive cases in 1993, including 13,500 cases of cancer of the cervix and 31,000 cases of cancer of the corpus (body) of the uterus, usually of the endometrium (lining). The incidence of invasive cervical cancer has steadily decreased over the years. Cervical carcinoma in situ, a precancerous condition, is now more frequent than invasive cancer, especially in women under 50. Endometrial cancer is most common in older women, diagnosis usually is made after age 50.

Mortality: An estimated 4,400 deaths in 1993 from cervical cancer and 5,700 from endometrial and unspecified uterine cancer. Overall, the death rate for uterine cancer has decreased more than 70% over the past 40 years, due mainly to regular checkups and the use of the Pap test for early detection of cervical cancer.

Warning Signals: Bleeding outside of the normal menstrual period or after menopause, or unusual vaginal discharge.

Risk Factors: For cervical cancer: early age at first intercourse, multiple sex partners, cigarette smoking, and certain sexually transmitted diseases. For endometrial cancer: early menarche, late menopause, history of infertility, failure to ovulate, tamoxifen or unopposed estrogen therapy, obesity.

During menopause, the level of hormones (estrogens) normally produced by the ovaries declines. This causes symptoms such as "hot flashes" or painful sexual intercourse due to thinning of the vaginal lining. To control these symptoms, estrogen replacement therapy is given to women during and after menopause. This therapy may increase the risk of endometrial cancer, therefore, the benefits and risks of such treatment should be discussed by the woman and her physician.

Early Detection: The Pap test is a simple procedure that can be performed at appropriate intervals by health care professionals as part of a pelvic examination. A small sample of cells is swabbed from the cervix and body of the uterus, transferred to a slide, and examined under a microscope. This test should be performed annually with a pelvic examination in women who are, or have been, sexually active or who have reached age 18 years. After three or more consecutive annual examinations with normal findings, the Pap test may be performed less frequently at the discretion of the physician. The Pap test, highly effective in detecting early cancer of the uterine cervix, is only partially effective in detecting endometrial cancer. Women 40 and over should have an annual pelvic exam by a health professional. Women at high risk of developing endometrial cancer should have an endometrial tissue sample evaluated at menopause.

Treatment: Uterine cancers generally are treated by surgery or radiation, or by a combination of the two. In precancerous (in situ) stages, changes in the cervix may be treated by cryotherapy (the destruction of cells by extreme cold), by electrocoagulation (the destruction of tissue through intense heat by electric current), or by local surgery. Precancerous endometrial changes may be treated with the hormone progesterone.

Survival: The 5-year survival rate for all cervical cancer patients is 66%. For patients diagnosed early, however, the survival rate is 89% and if the disease is in situ, the rate is virtually 100%. In endometrial cancer, survival rates are 83% overall, 94% if discovered at an early stage, and 68% in a regional stage.

Cancer in Children

Incidence: An estimated 8,000 new cases in 1993; as a childhood disease, cancer is rare. Common sites include the blood and bone marrow, bone, lymph nodes, brain, nervous system, kidneys, and soft tissues.

Mortality: An estimated 1,500 deaths in 1993, about one-third of them from leukemia. Despite its rarity, cancer is the chief cause of death by disease in children between the ages of 1 and 14. Mortality rates have declined 60% since 1950.

Early Detection: Cancers in children often are difficult to recognize. Parents should see that their children have regular medical checkups and should be alert to any unusual symptoms that persist. These include: an unusual mass or swelling; unexplained paleness and loss of energy; sudden tendency to bruise; a persistent, localized pain or limping; prolonged, unexplained fever or illness; frequent headaches, often with vomiting; sudden eye or vision changes; and excessive, rapid weight loss.

Some of the main childhood cancers are:

Leukemia, next column.

Osteogenic sarcoma and Ewing's sarcoma are bone cancers. These may cause no pain at first, and swelling in the area of the tumor is often the first sign.

Neuroblastoma can appear anywhere but usually in the abdomen, where a swelling occurs.

Rhabdomyosarcoma, the most common soft tissue sarcoma, can occur in the head and neck area, genito-urinary area, trunk, and extremities.

Brain cancers in early stages may cause headaches, blurred or double vision, dizziness, difficulty in walking or handling objects, and nausea.

Lymphomas and Hodgkin's disease are cancers that involve the lymph nodes, but also may invade bone marrow and other organs. They may cause swelling of lymph nodes in the neck, armpit, or groin. Other symptoms may include general weakness and fever.

Retinoblastoma, an eye cancer, usually occurs in children under age four. When detected early, cure is possible with appropriate treatment.

Wilms' tumor, a kidney cancer, may be recognized by a swelling or lump in the abdomen.

Treatment: Childhood cancers can be treated by a combination of therapies. Treatment is coordinated by a team of experts including oncologic physicians, pediatric nurses, social workers, psychologists, and others who assist children and their families.

Survival: Five-year survival rates vary considerably, depending on the site: all sites 68%; bone cancer, 56%; neuroblastoma, 55%; brain and central nervous system, 59%; Wilms' tumor (kidney), 87%; Hodgkin's disease, 88%; and acute lymphocytic leukemia, 72%.

Leukemia

Incidence: An estimated 29,300 new cases in 1993, approximately evenly divided into acute leukemia and chronic leukemia. Although often thought of as primarily a childhood disease, leukemia will strike many more adults (26,700 this year) than children (2,600 this year). Acute lymphocytic leukemia accounts for approximately 2,000 of the cases of leukemia among children. In adults, the most common types are acute granulocytic (approximately 6,800 cases) and chronic lymphocytic (approximately 8,600 cases).

Mortality: An estimated 18,600 deaths in 1993.

Warning Signals: Early signs may include fatigue, paleness, weight loss, repeated infections, bruising easily, and nosebleeds or other hemorrhages. In children, these symptoms can appear suddenly. Chronic leukemia can progress slowly and with few symptoms.

Risk Factors: Leukemia strikes both sexes and all ages. Causes of most cases are unknown. Persons with Down syndrome and certain other genetic abnormalities have higher than normal incidence of leukemia. It has also been

linked to excessive exposure to ionizing radiation and to certain chemicals such as benzene, a commercially used toxic liquid that is also present in lead-free gasoline. Certain forms of leukemia and lymphoma are caused by a retrovirus, HTLV-I (human T-cell leukemia/lymphoma virus-I).

Early Detection: Because symptoms often resemble those of other, less serious conditions, leukemia can be difficult to diagnose early. When a physician does suspect leukemia, diagnosis can be made using blood tests and biopsy of the bone marrow.

Treatment: Chemotherapy is the most effective method of treating leukemia. Various anticancer drugs are used, either in combinations or as single agents. Transfusions of blood components and antibiotics are used as supportive treatments. To prevent persistence of hidden cells, therapy of the central nervous system has become standard treatment, especially in acute lymphocytic leukemia. Under appropriate conditions, bone marrow transplantation may be useful in the treatment of certain leukemias.

Survival: The 5-year survival rate for patients with leukemia is 37%, due partly to very poor survival of patients with some types of leukemia such as acute granulocytic. Over the last 30 years, however, there has been a dramatic improvement in survival of patients with acute lymphocytic leukemia; from a 5-year survival rate of 4% for people diagnosed in the early 1960s to 28% in the early 1970s to 51% in the mid 1980s. In children, the improvement has been from 4% to 72%.

Lymphoma

Incidence: An estimated 50,900 new cases in 1993, including 7,900 cases of Hodgkin's disease and 43,000 non-Hodgkin's lymphoma. Since the early 1970s, incidence rates for non-Hodgkin's lymphoma have increased, particularly in persons over age 65. Incidence of Hodgkin's disease has declined significantly over the same time period, especially among the elderly.

Mortality: An estimated 22,000 deaths in 1993 (non-Hodgkin's lymphoma, 20,500; Hodgkin's disease, 1,500).

Warning Signals: Hodgkin's disease: enlarged lymph nodes, itching, fever, night sweats, and weight loss. Fever can come and go in periods of several days or weeks. Non-Hodgkin's lymphoma: enlarged lymph nodes, anemia, weight loss, and fever.

Risk Factors: Risk factors are largely unknown but in part involve reduced immune function and exposure to certain infectious agents. Persons with organ transplants are at higher risk due to altered immune function. Human immunodeficiency virus (HIV) and human T-cell leukemia/lymphoma virus-I (HTLV-I) are associated with increased risk of non-Hodgkin's lymphoma. Burkitt's lymphoma in Africa is partly caused by the Epstein-Barr herpes virus. Other possible risk factors include exposures to herbicides, industrial solvents, and vinyl chloride.

Treatment: Hodgkin's disease: chemotherapy and radiotherapy are useful for most patients. Non-Hodgkin's lymphoma: early stage, localized lymph node disease can be treated with radiotherapy. Patients with later stage disease often benefit from the addition of chemotherapy. New programs using highly specific monoclonal antibodies directed at lymphoma cells, and improved techniques in bone marrow preservation, are under investigation in selected patients who relapse after standard treatment.

Survival: Survival rates vary widely by cell type and stage of disease. The overall 5-year survival rate for Hodgkin's disease is 77%. The overall 5-year survival for non-Hodgkin's lymphoma has steadily improved, and in the past 30 years has increased from 31% to 51%.

Skin Cancer

Incidence: Over 700,000 cases a year of highly curable basal cell or squamous cell cancers. They are more common among individuals with lightly pigmented skin. The most serious skin cancer is melanoma, which will be diagnosed in about 32,000 persons in 1993. Since 1973, the incidence rate of melanoma has increased about 4% per year. Incidence rates are over ten times higher among whites than blacks. An additional 10,000 invasive nonmelanoma skin cancers will occur in 1993, mostly sarcomas, including Kaposi's sarcoma.

Mortality: An estimated 9,100 deaths this year, 6,800 from malignant melanoma and 2,300 due to other skin cancers.

Warning Signals: Any unusual skin condition, especially a change in the size or color of a mole or other darkly pigmented growth or spot. Scaliness, oozing, bleeding, or change in the appearance of a bump or nodule, the spread of pigmentation beyond its border, a change in sensation, itchiness, tenderness, or pain are all warning signs of melanoma.

Risk Factors: Excessive exposure to ultraviolet radiation; fair complexion; occupational exposure to coal tar, pitch, creosote, arsenic compounds, or radium.

Prevention: The sun's ultraviolet rays are strongest between 10 a.m. and 3 p.m.. Exposure at these times should be avoided, and protective clothing should be worn. Sunscreens should be used. These come in various strengths, ranging from those facilitating gradual tanning to those that allow practically no tanning. Because of the possible link between severe sunburns in childhood and greatly increased risk of melanoma in later life, children, in particular, should be protected from the sun.

Early Detection: Early detection is critical. Recognition of changes in skin growths or the appearance of new growths is the best way to find early skin cancer. Adults should practice skin self-examination once a month, and

How to Estimate Cancer Statistics Locally

Estimated number of...	Number per 100,000	Multiply community population by	Special Notes
New cancer cases, 1993	400	0.004	Estimated cases and deaths will not reflect the age and ethnic characteristics of the population, access to detection and treatment, and varying risk factors. Actual data from a population-based tumor registry will allow more accurate estimates.
Cancer deaths, 1993	200	0.002	
Cancer survivors, 1993	2,000	0.020	Represents the number of people who were diagnosed over 5 years ago and are still living today.
Cancer cases under care, 1993	1,600	0.016	Represents the number of people diagnosed in 1993 and within the last 5 years. All are assumed to be under treatment or follow-up care.
People who will eventually develop cancer	34,000	0.340	If current incidence and mortality rates remain the same, about 34% or 1 in 3 people will develop cancer by age 85.
People who will eventually die of cancer	20,000	0.200	If current mortality rates remain the same, about 1 in 5 people living today will die of cancer.
People who will be saved from cancer in 1993	200	0.002	Based on 5-year relative survival rate of 52%.

Note: The figures are only a rough approximation of actual data for a community and should be used with caution. Numbers may vary according to the age distribution of the local population.

suspicious lesions should be evaluated promptly by a physician. Basal and squamous cell skin cancers often take the form of a pale, waxlike, pearly nodule, or a red, scaly, sharply outlined patch. A sudden or progressive change in a mole's appearance should be checked by a physician. Melanomas often start as small, mole-like growths that increase in size, change color, become ulcerated, and bleed easily from a slight injury. A simple ABCD rule outlines the warning signals of melanoma: A is for asymmetry. One half of the mole does not match the other half. B is for border irregularity. The edges are ragged, notched, or blurred. C is for color. The pigmentation is not uniform. D is for diameter greater than 6 millimeters. Any sudden or progressive increase in size should be of special concern.

Treatment: There are four methods of treatment: surgery (used in 90% of cases), radiation therapy, electrodessication (tissue destruction by heat), or cryosurgery (tissue destruction by freezing) for early skin cancer. For malignant melanoma, the primary growth must be adequately excised, and it may be necessary to remove nearby lymph nodes. Removal and microscopic examination of all suspicious moles is essential. Advanced cases of melanoma are treated according to the characteristics of the case.

Survival: For basal cell or squamous cell cancers, cure is highly likely if detected and treated early. Malignant melanoma can spread to other parts of the body quickly; however, when detected in its earliest stages, and with proper treatment, it is highly curable.

The overall 5-year survival rate for patients with malignant melanoma is 83%. The 5-year survival rate for localized malignant melanoma is 91%; survival rates for regional and distant disease are 54% and 13%, respectively. About 81% of melanomas are diagnosed in a local stage.

Ovary Cancer

Incidence: An estimated 22,000 new cases in the United States in 1993. It is estimated that one of every 65 women will develop ovarian cancer by age 85. It accounts for 4% of all cancers among women.

Mortality: An estimated 13,300 deaths in 1993. Although ovarian cancer ranks second in incidence among gynecological cancers, it causes more deaths than any other cancer of the female reproductive system.

Warning Signals: Ovarian cancer is often "silent," showing no obvious signs or symptoms until late in its development. The most common sign is enlargement of the abdomen, which is caused by the accumulation of fluid. Rarely will there be abnormal vaginal bleeding. In women over 40, vague digestive disturbances (stomach discomfort, gas, distention) that persist and cannot be explained by any other cause may indicate the need for a thorough evaluation for ovarian cancer.

Risk Factors: Risk for ovarian cancer increases with age. The highest rates are for women over 60. Women who have never had children are twice as likely to develop ovarian cancer as those who have. Early age at first pregnancy, early menopause, and the use of oral contraceptives, which reduces the frequency of ovulation, appear to be protective against ovarian cancer. If a woman has had breast cancer, her chances of developing ovarian cancer double. Certain rare genetic disorders are associated with increased risk. With the exception of Japan, the

Trends in Cancer Survival, by Race
Cases Diagnosed in 1960-63, 1970-73, 1974-76, 1977-79, 1983-88

	White					Black				
	Relative 5-Year Survival					Relative 5-Year Survival				
Site	1960-63[1]	1970-73[1]	1974-76[1]	1977-79[1]	1983-88[1]	1960-63[1]	1970-73[1]	1974-76[1]	1977-79[1]	1983-88[1]
All sites	39	43	50	51	54*	27	31	39	39	38
Oral cavity & pharynx	45	43	55	54	54	—	—	36	36	32
Esophagus	4	4	5	6	9*	1	4	4	3	6*
Stomach	11	13	14	16	16*	8	13	16	15	17
Colon	43	49	50	53	59*	34	37	46	48	48*
Rectum	38	45	49	50	57*	27	30	42	38	46
Liver	2	3	4	3	6*	—	—	1	6	5
Pancreas	1	2	3	2	3*	1	2	2	4	5*
Larynx	53	62	66	68	67	—	—	59	55	53
Lung & bronchus	8	10	12	14	13*	5	7	11	11	11
Melanoma of skin	60	68	80	82	83*	—	—	69†	52‡	68†
Female breast	63	68	75	75	79*	46	51	63	63	62
Cervix uteri	58	64	69	69	68	47	61	63	62	55*
Corpus uteri	73	81	89	86	84*	31	44	60	58	54
Ovary	32	36	36	38	39*	32	32	41	40	37
Prostate	50	63	68	72	78*	35	55	58	62	63*
Testis	63	72	79	88	93*	—	—	76†	—	84†
Urinary bladder	53	61	74	76	79*	24	36	48	55	59*
Kidney & renal pelvis	37	46	52	51	55*	38	44	49	52	53
Brain & nervous system	18	20	22	24	25*	19	19	27	28	32
Thyroid gland	83	86	92	92	94*	—	—	87	92	93
Hodgkin's disease	40	67	72	73	78*	—	—	69	73	74
Non-Hodgkin's lymphoma	31	41	48	48	52*	—	—	48	50	43
Multiple myeloma	12	19	24	25	26*	—	—	27	34	29
Leukemia	14	22	35	37	38*	—	—	31	30	29

Source: Cancer Statistics Branch, National Cancer Institute.
[1]Rates are based on End Results Group data from a series of hospital registries and one population-based registry.
*Rates are from the SEER Program. They are based on data from population-based registries in Connecticut, New Mexico, Utah, Iowa, Hawaii, Atlanta, Detroit, Seattle-Puget Sound and San Francisco-Oakland. Rates are based on follow up of patients through 1989.
*The difference in rates between 1974-76 and 1983-88 is statistically significant ($p < 0.05$). †The standard error of the survival rate is between 5 and 10 percentage points. ‡The standard error of the survival rate is greater than 10 percentage points. —Valid survival rate could not be calculated.

highest incidence rates are reported from the more industrialized countries.

Early Detection: Periodic, thorough pelvic examinations are important. The Pap test, useful in detecting cervical cancer, does not reveal ovarian cancer. Women over the age of 40 should have a cancer-related checkup every year.

Treatment: Surgery, radiation therapy, and drug therapy are treatment options. Surgery usually includes the removal of one or both ovaries (oophorectomy), the uterus (hysterectomy), and the fallopian tubes (salpingectomy). In some very early tumors, only the involved ovary will be removed, especially in young women. In advanced disease, an attempt is made to remove all intraabdominal disease, to enhance the effect of chemotherapy.

Survival: Overall, the 5-year survival rate for ovarian cancer is 39%. If diagnosed and treated early, the relative survival rate is 89%; however, only about 23% of all cases are detected at the localized stage. Survival rates for women with regional and distant disease are 37% and 18%, respectively.

Bladder Cancer

Incidence: An estimated 52,300 new cases in 1993; 39,000 in men, 13,300 in women. Overall, the incidence rate of bladder cancer is four times greater among men than among women, and is higher in whites than in blacks.

Mortality: An estimated 9,900 deaths in 1993.

Warning Signals: Blood in the urine. Usually associated with increased frequency of urination.

Risk Factors: Smoking is the greatest risk factor in bladder cancer, with smokers experiencing twice the risk of nonsmokers. Smoking is estimated to be responsible for approximately 47% of the bladder cancer deaths among men and 37% among women. People living in urban areas and workers exposed to dye, rubber, or leather also are at higher risk.

Early Detection: Bladder cancer is diagnosed by examination of the bladder wall with a cystoscope, a slender tube fitted with a lens and light that can be inserted into the tract through the urethra.

Treatment: Surgery, alone or in combination with other treatments is used in over 90% of cases. Preoperative chemotherapy alone or with radiation before cystectomy (bladder removal) has improved some treatment results.

Survival: When detected at an early stage, the 5-year survival rate for bladder cancer is 90%. For regional and distant disease, the survival rates are 46% and 9%, respectively.

Oral Cancer

Incidence: An estimated 29,800 new cases in 1993. Incidence is more than twice as high in men as in women, and is most frequent in men over age 40.

Mortality: An estimated 7,700 deaths in 1993.

Warning Signals: A sore that bleeds easily and doesn't heal; a lump or thickening; a red or white patch that persists. Difficulty in chewing, swallowing, or moving tongue or jaws are often late changes.

Risk Factors: Cigarette, cigar, or pipe smoking; use of smokeless tobacco; excess use of alcohol.

Early Detection: Cancer can affect any part of the oral cavity, including the lip, tongue, mouth, and throat. Dentists and primary care physicians have the opportunity, during regular checkups, to see abnormal tissue changes and to detect cancer at an early, curable stage.

Treatment: Principal methods are radiation therapy and surgery. Chemotherapy is being studied as an adjunct to surgery in advanced disease.

Survival: Five-year survival rates vary substantially, depending on the site. Rates range from 23% for cancer of the hypopharynx to 93% for lip cancer. Overall, 5-year survival for oral cancer patients is about 52%.

Cancer in Minorities

In 1993, about 1,170,000 cancers will be diagnosed in the United States. About 120,000 of these cancers will be among black Americans and 33,000 among other minority Americans.

Cancer incidence and mortality rates are generally higher for black Americans than for whites. In 1989, the incidence rates were 401 per 100,000 for blacks and 380 for whites, about a 6% difference. In 1989, the mortality rates were 227 for blacks and 169 for whites.

Cancer sites where blacks have significantly higher incidence and mortality rates include esophagus, uterine cervix, stomach, liver, prostate, larynx, and multiple myeloma. Rates for esophageal cancer are over three times higher among blacks than whites.

The 5-year survival rate for cancer in blacks diagnosed from 1983 through 1988 was about 38% compared with 54% for whites. A considerable part of this difference in survival can be attributed to late diagnosis. Many cancers are more frequently diagnosed in a localized stage among whites than among blacks. Most of these sites represent cancers for which screening tests are available or which present symptoms early in the disease process. Early detection and timely treatment can increase survival.

Incidence and mortality rates for other minority groups such as Hispanics are often lower than those for white or black Americans. Because cancer risk is strongly associated with lifestyle and behavior, differences in ethnic and cultural groups can provide clues to factors involved in the development of cancer such as dietary patterns, alcohol use, and sexual and reproductive behaviors involved in the development of cancer. Cultural values and belief systems can affect attitudes about seeking medical care or following screening guidelines (see p. 21). Socioeconomic factors such as lack of health insurance or transportation can impede access to care, and lead to late diagnosis and poor survival.

Number of Cancer Deaths for Black, American Indian, Chinese, Japanese, and Hispanic Persons, United States, 1989

Cancer Site	Black Males	Black Females	American Indian	Chinese	Japanese	Hispanic*
All sites	31,452	24,112	1,318	1,425	1,124	13,538
Oral cavity	939	312	23	62	14	209
Esophagus	1,524	523	20	28	29	257
Stomach	1,390	859	54	86	139	793
Colon & rectum	2,765	3,080	131	169	164	1,327
Liver & other biliary	791	568	85	153	53	754
Pancreas	1,403	1,551	74	68	84	690
Lung (male)	10,457	—	221	239	139	1,789
Lung (female)	—	4,246	118	134	78	800
Breast (female)	—	4,403	90	62	78	1,115
Cervix uteri	—	1,049	31	19	10	274
Other uterus	—	873	12	22	9	159
Ovary	—	901	26	31	34	365
Prostate	4,785	—	71	40	36	889
Bladder	484	369	14	8	26	224
Kidney	525	363	46	14	18	334
Brain & CNS	335	299	30	22	10	373
Lymphoma	750	558	40	45	52	722
Leukemia	868	672	45	50	37	645
Multiple myeloma	684	703	30	13	8	271

*Persons classified as Hispanic origin on death certificates may be of any race. Hispanic deaths in 1989 were reported in 44 states and the District of Columbia. Hispanic deaths in the following six states are not included: Connecticut, Louisiana, Maryland, New Hampshire, Oklahoma, and Virginia. In 1980, the reporting areas accounted for about 97% of the Hispanic population in the United States. Caution should be exercised in generalizing this mortality data to the entire United States Hispanic population.

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Prevention

Smoking

Cigarette smoking is responsible for 90% of lung cancer cases among men and 79% among women—about 87% overall. Smoking accounts for about 30% of all cancer deaths. Those who smoke two or more packs of cigarettes a day have lung cancer mortality rates 15 to 25 times greater than nonsmokers. (See Tobacco Use.)

Sunlight

Almost all of the more than 700,000 cases of basal and squamous cell skin cancer diagnosed each year in the US are sun-related (ultraviolet radiation). Epidemiologic evidence shows that sun exposure is a major factor in the development of melanoma and that incidence increases for those living near the equator. (See Selected Cancers: Skin Cancer.)

Ionizing Radiation

Excessive exposure to ionizing radiation can increase cancer risk. Most medical and dental x-rays are adjusted to deliver the lowest dose possible without sacrificing image quality. Excessive radon exposure in homes may increase risk of lung cancer, especially in cigarette smokers. If levels are found to be too high, remedial actions should be taken.

Nutrition and Diet

Research is showing the important role nutrition plays in preventing cancer. Evidence indicates that people may reduce their cancer risk by observing these nutrition guidelines:

1. Maintain desirable weight. Individuals 40% or more overweight increase their risk of colon, breast, prostate, gallbladder, ovary, and uterus cancers. Physicians can recommend a suitable diet and exercise regimen to help maintain appropriate weight and body fitness.

2. Eat a varied diet. A varied diet eaten in moderation offers the best hope for lowering the risk of cancer.

3. Include a variety of vegetables and fruits in the daily

diet. Studies have shown that daily consumption of vegetables and fresh fruits is associated with a decreased risk of lung, prostate, bladder, esophagus, colorectal, and stomach cancers.

4. Eat more high-fiber foods such as whole grain cereals, breads, and pasta; vegetables, and fruits. High-fiber diets are a healthy substitute for fatty foods and may reduce the risk of colon cancer.

5. Cut down on total fat intake. A diet high in fat may be a factor in the development of certain cancers, particularly breast, colon, and prostate.

6. Limit consumption of alcohol, if you drink at all. The heavy use of alcohol, especially when accompanied by cigarette smoking or smokeless tobacco use, increases risk of cancers of the mouth, larynx, throat, esophagus, and liver.

7. Limit consumption of salt-cured, smoked, and nitrite-cured foods. In areas of the world where salt-cured and smoked foods are eaten frequently, there is higher incidence of cancer of the esophagus and stomach. Modern methods of food processing and preserving appear to avoid the cancer-causing byproducts associated with older methods of food treatment.

Alcohol

Oral cancer and cancers of the larynx, throat, esophagus, and liver occur more frequently among heavy drinkers of alcohol especially when accompanied by smoking cigarettes or chewing tobacco. (See Selected Cancers: Oral Cancer.)

Smokeless Tobacco

Use of chewing tobacco or snuff increases risk of cancer of the mouth, larynx, throat, and esophagus and is a highly addictive habit. (See Selected Cancers: Oral Cancer.)

Estrogen

Estrogen treatment to control menopausal symptoms can increase risk of endometrial cancer. However, including progesterone in estrogen replacement therapy helps to minimize this risk. Consultation with a physician will help each woman to assess personal risks and benefits. Continued research is needed in the area of estrogen use and breast cancer. (See Selected Cancers: Uterus and Cervix Cancer).

Occupational Hazards

Exposure to several different industrial agents (nickel, chromate, asbestos, vinyl chloride, etc.) increases risk of various cancers. Risk of lung cancer from asbestos is greatly increased when combined with cigarette smoking. (See Environmental Cancer Risk Assessment.)

Environmental Cancer Risk Assessment

Evaluating the degree of cancer hazard posed by particular environmental risks is essential for developing environmental standards which protect people against unsafe exposure to chemicals and radiation. Assessment involves 1) identifying toxic properties of potentially oncogenic hazards and 2) measuring the extent of human exposure.

The first step, **hazard identification**, characterizes the chemical or physical nature of hazards and evaluates their toxicity both in observed human exposures and in laboratory tests using animals or cells. Special emphasis is given to evidence suggesting that cancer risk may increase with dose (dose-response relationships).

The second step, **exposure measurement**, determines concentration level of hazards in the environment (air, water, food, medications, workplace) and the extent to which people are actually exposed (how much they eat of a particular food, use particular medication, etc.) The true carcinogenic dose delivered to tissues and cells is estimated from information regarding pathways by which the body absorbs, metabolizes, and excretes toxins.

For most potential carcinogens, risk assessment involves two stages at which extrapolation of information is required: extrapolation of observed animal toxicity to what might be expected in humans and extrapolation of effects seen at high doses to what might be expected at low doses. In both procedures, conservative assumptions are made so that if risk assessment is in error, it will have erred on the side of safety. For cancer safety standards, only increased risks of one case or less per million persons per lifetime are usually accepted.

Such safety standards for chemical or radiation exposures form the basis for regulatory activities at the Food and Drug Administration, the Environmental Protection Agency, and the Occupational Safety and Health Administration. The development of laws and procedures by which standards are implemented and risks are controlled is called "Risk Management."

Early Detection

Guidelines for the early detection of cancer in people without symptoms are recommended by the American Cancer Society as follows: A cancer-related checkup by a physician every three years for persons age 20-39 and annually for those age 40 and over. Some persons at particular risk for certain cancers may need tests more often and should discuss this with their doctor. The checkup should always include health counseling (how to quit smoking, etc.) and exams for cancer of the breast, uterus, cervix, colon, rectum, prostate, mouth, skin, testes, thyroid, and lymph nodes.

Breast

The American Cancer Society recommends that screening mammography begin by age 40. Women age 40-49 should have mammography every 1-2 years, depending on physical and mammographic findings. Women age 50 and older should have mammograms yearly. The ACS recommends the monthly practice of breast self-exam (BSE) by women 20 years and older as a routine good health habit. Examination of the breast by a health care professional should be done every three years from ages 20-40 and then every year.

Colon and Rectum

The American Cancer Society recommends three tests for the early detection of colon and rectum cancer in people without symptoms. A digital rectal examination by a physician during an office visit should be performed every year after the age of 40; the stool blood test is recommended every year after age 50; and sigmoidoscopy, preferably flexible, should be performed every 3 to 5 years.

Uterine and Cervical

For cervical cancer, women who are or have been sexually active, or have reached age 18, should have an annual Pap test and pelvic examination. After a woman has had three or more consecutive satisfactory normal annual examinations, the Pap test may be performed less frequently at the discretion of her physician. Women age 40 and over should have an annual pelvic examination.

Prostate

Men who have reached 40 years of age and older should have a digital rectal examination (DRE) annually. Annual prostate-specific antigen blood testing should be performed on men age 50 and older.

Tobacco Use

Smoking is the most preventable cause of death in our society. Tobacco use is responsible for more than one in six deaths in the United States. Based upon data from the American Cancer Society's Cancer Prevention Study II (CPS-II), it is estimated that smoking is related to over 400,000 US deaths each year. According to the World Health Organization, approximately 2.5 million people die worldwide each year as a result of smoking.

In addition to being responsible for 87% of lung cancers, smoking is also associated with cancers of the mouth, pharynx, larynx, esophagus, pancreas, uterine cervix, kidney, and bladder. Smoking accounts for 30% of all cancer deaths, is a major cause of heart disease, and is associated with conditions ranging from colds and gastric ulcers to chronic bronchitis, emphysema, and cerebrovascular disease.

A Decline in Smoking

The National Health Interview Survey (NHIS) reports that cigarette smoking among adults ages 18 and over declined from 42% in 1965 to 25% in 1990. The NHIS data from 1974 to 1990 show:

- smoking among men dropped from 43% to 24%.
- smoking among women decreased from 33% to 23%.
- rates for college graduates declined from 28% to 14%.
- rates for persons without a high school education decreased slightly from 44% to 37%.

According to the 1989 Surgeon General's Report, decisions to quit or not to start through 1985 will postpone or prevent an additional 2 million smoking-related deaths between 1986 and and the year 2000.

Per capita cigarette consumption dropped about 35% from 1973-1991 (4,148 to 2,713). This is the lowest per capita cigarette consumption since 1942.

Profile of Smokers

In 1990, number of current smokers in the US: 46 million. The prevalence of smoking is highest among men who

do not have a high school education.

Approximately 50% of smokers start smoking regularly before age 18.

More than 3,000 teenagers become regular smokers each day in the US.

According to the Centers for Disease Control's 1991 Youth Risk Behavior Survey:

- 70% of all students in grades 9-12 reported ever trying cigarettes.
- About 13% of high school students reported frequent cigarette use.

Cost of Tobacco

A 1985 report by the US Congress Office of Technology Assessment estimates:

- The total cost of smoking to the economy to be about $65 billion annually.
- The cost of treating smoking-related diseases and lost productivity amounts to $2.17 for each pack of cigarettes sold.

Cigarette Exports

US cigarette exports have increased due to aggressive marketing by tobacco companies, and expanding foreign markets. A September 1992 tobacco report of the US Department of Agriculture estimates:

- US cigarette exports have increased about 200% since 1985.
- US cigarette exports to Japan have increased over 700%, from 6.5 billion in 1985 to 54 billion in 1991.
- Exports to South Korea have grown from 0.3 billion in 1987 to 4 billion in 1991.
- US cigarette output from July 1990 to June 1991 was 685 billion. These provisional data indicate a decline in production that may continue as the US tobacco industry builds manufacturing operations overseas.

Nicotine Addiction

Tobacco smoke contains over 4,000 chemical compounds including at least 43 different carcinogenic substances.

The 1988 Surgeon General's Report on Nicotine Addiction concluded:

- cigarettes and other forms of tobacco are addicting.
- nicotine is the drug in tobacco that causes addiction.
- the pharmacologic and behavioral processes that determine tobacco addiction are similar to those that determine addiction to drugs such as hernin and cocaine.

Nicotine is found in substantial amounts in tobacco smoke. It is absorbed readily from tobacco smoke in the lungs and from smokeless tobacco in the mouth or nose and is rapidly distributed throughout the body.

Smoking Cessation

By 1990, more than 44 million Americans had quit smoking cigarettes, nearly half of all living adults who ever smoked.

Between 1987 and 1990, smoking rates declined more than twice as fast as in the time period from 1965-1985.

In September 1990, the Surgeon General outlined the benefits of smoking cessation:

- People who quit smoking, regardless of age, live longer than people who continue to smoke.
- Smokers who quit before age 50 have half the risk of dying in the next 15 years compared with those who continue to smoke.
- Quitting smoking decreases substantially the risk of lung, laryngeal, esophageal, oral, pancreatic, bladder, and cervical cancers.
- Benefits of cessation include risk reduction for other major diseases including coronary heart disease and cardiovascular disease.

A 1989 Gallup Survey reports the following people want to quit smoking:

- 57% of smokers 50 and older
- 67% of smokers aged 30-49
- 68% of smokers aged 18-29.

Involuntary Smoking Hazards

People who do not smoke, but who are exposed to the tobacco smoke of others are at increased risk for certain diseases.

Environmental tobacco smoke (ETS):

- causes an estimated 53,000 deaths annually in the United States, about two-thirds from heart disease, and about 4,000 from lung cancer.
- can result in aggravated asthmatic conditions and impaired blood circulation.
- has significantly higher concentrations of the toxic and carcinogenic compounds found in mainstream smoke.
- has been classified as a Class A (known human) carcinogen by the Environmental Protection Agency.
- poses additional health hazards for unborn and young children. Children exposed to secondhand smoke have increased risks of respiratory illnesses and infections, impaired development of lung function, and middle ear infections. Infants born to women who smoked during pregnancy are more likely to die from Sudden Infant Death syndrome.

Nine million American children under the age of five may be exposed to ETS, according to the American Academy of Pediatrics.

Smokeless Tobacco

There has been a resurgence in the use of all forms of smokeless tobacco—plug, leaf, and snuff—but the greatest cause for concern centers on the increased use of "dipping snuff." In this practice, tobacco that has been processed into a coarse, moist powder is placed between

the cheek and gum, and nicotine, along with a number of carcinogens, is absorbed through the oral tissue.

Dipping snuff is highly addictive, and exposes the body to levels of nicotine equal to those of cigarettes.

A 1986 report of the Advisory Committee to the Surgeon General concluded:

- there is strong, scientific evidence that the use of snuff causes cancer in humans, particularly cancer of the oral cavity.
- oral cancer occurs several times more frequently among snuff dippers compared with non-tobacco users.
- the excess risk of cancer of the cheek and gum may reach nearly fifty-fold among long-term snuff users.
- in 1985, smokeless tobacco was used by at least 12 million people in the United States, and half of those were regular users.
- the use of smokeless tobacco is increasing among male adolescents and young male adults.

The CDC's 1991 Youth Risk Behavior Survey reported:

- **19% of male high school students used smokeless tobacco.**

Industrial Hazards

Industrial workers are especially susceptible to lung diseases due to the combined effects of cigarette smoke and exposure to certain toxic industrial substances, such as fumes from rubber and chlorine, and dust from cotton and coal. Exposure to asbestos in combination with cigarette smoking increases an individual's lung cancer risk nearly 60 times. Smoking also enhances lung cancer risk in underground miners exposed to radon.

The American Cancer Society

Profile

The American Cancer Society traces its origins to 1913, when a group of 10 physicians and five laymen met in New York City and founded the American Society for the Control of Cancer. Its stated purpose at the time was to "disseminate knowledge concerning the symptoms, treatment, and prevention of cancer; to investigate conditions under which cancer is found; and to compile statistics in regard thereto." Later renamed the American Cancer Society, Inc., it is today one of the oldest and largest voluntary health agencies in the United States, with over 2 million Americans united to conquer cancer through balanced programs of research, education, patient service, and rehabilitation.

Organization: The American Cancer Society, Inc., consists of a National Society, with 57 chartered Divisions and over 3,400 Units.

The National Society: A 284-member Board of Directors provides a basic representation from the 57 Divisions and additional representation on the basis of population.

The National Society is responsible for overall planning and coordination; provides technical help and materials to Divisions and Units; administers programs of research, medical grants and clinical fellowships; and carries out public and professional education on the national level.

The 57 Divisions: These are governed by members of Divisional Boards of Directors, both medical and lay, in all the states plus five metropolitan areas, the District of Columbia and Puerto Rico.

The Units: These are organized to cover the counties in the United States. There are thousands of community leaders who direct the Society's programs at this level.

The Programs: The Society maintains its priorities and goals through activities developed by the departments of Research, Detection and Treatment, Prevention, Public Information, Communications, Epidemiology and Statistics, Patient Services, Advocacy, and Income Development. Some of the larger programs are outlined below.

Research

The aim of the Society's research program is to determine what causes cancer and to support efforts to prevent and cure cancer. The American Cancer Society is the largest private source of cancer research funds in the United States, second in total dollars spent only to the National Cancer Institute, an agency of the federal government.

The Society's overall annual expenditure in research has grown steadily from $1 million in 1946 to approximately $89 million in fiscal year 1992. This sum represents slightly over 25% of the total expenditures of the Society. To date, the Society has invested more than $1.5 billion in cancer research. The success of the Society's research program is attested to by the fact that 25 Nobel Prize winners received grant support from the American Cancer Society early in their careers.

The Research Program

The research program supports outside investigators, and

focuses primarily on investigator-initiated projects. With the exception of staff and facilities to carry out its epidemiologic studies, the American Cancer Society neither hires staff researchers nor operates its own laboratories. This gives the Society the freedom to place its grants in leading centers across the country where the most innovative and promising ideas are being explored. In this way there is minimum overhead and maximum flexibility.

Applications for American Cancer Society grants are subjected to a rigorous process of external peer review as follows:

- The application is studied carefully by the appropriate one of 14 Scientific Advisory Committees.
- The application then goes to the Council for Research and Clinical Investigations, where the rank order of the applications approved by the Scientific Advisory Committee is examined. The Council recommends a payline based on the quality of the applications and the amount of money available.
- The Research and Clinical Investigations Committee of the Board of Directors reviews the payline and recommends the level of funding to the Board of Directors.
- The Board of Directors makes the final funding decisions. In order to maintain the integrity of the program, no member of a Scientific Advisory Committee or Council may serve on the Research and Clinical Investigation Committee or the National Board of Directors.

Types of Grants

The American Cancer Society Research Program offers five major types of grants: (1) Research and Clinical Investigation Grants to finance specific research projects; (2) Research Personnel Grants to provide salary support, for both established scientists and postdoctoral fellows specializing in cancer research; (3) Institutional Research Grants to universities, institutes and hospitals to support pilot studies by new investigators; (4) Research Development Program Grants to provide rapid funding for priority projects; and (5) Special Institutional Grants to provide long-term funding for interdisciplinary projects.

Approximately 75% of the Society's research budget is made available to investigators in the form of Research and Clinical Investigation Grants, slightly more than 18% is allocated to the Research Personnel Grants Program and the remaining 6%-7% is distributed among the Institutional Research Grants Program, the Research Development Program, and the Special Institutional Grants Program. Special Institutional Grants on psychosocial and behavioral research and on nutrition are being funded as high priority areas.

The following awards are unique and deserve special mention.

Research Professorships. In existence since 1957, these awards support some of the nation's most gifted scientists from mid-career until retirement, and free the scientists from major administrative responsibilities and other restrictions, so they can concentrate on their fields of scientific investigation. At the close of 1992, there were 24 Research Professors.

Clinical Research Professorships. These awards, which are similar to the Research Professorships, were initiated in 1987 to provide long-term support for outstanding clinician-scientists who bridge the gap between basic science and clinical medicine. Five such awards were in effect at the end of fiscal year 1992.

Physician's Research Training Fellowships. Started in 1981 to attract more MDs to cancer research, these grants provide an opportunity for physicians to take three years from their medical careers to train as researchers.

Research Development Program. This unique program was established to identify and provide funding for projects demonstrating unusually novel ideas or urgent needs. Approved applications can be funded in less than three months compared with the nine months it may take to fund a new project through regular channels.

Epidemiology

While most of the Society's research funding goes to support the work of outside investigators, ACS has long supported an active program of epidemiologic research within its National office. This program analyzes trends in cancer occurrence (*Facts and Figures* is an example) and has conducted three large prospective studies of cancer risk in American populations over the past 40 years.

- The Hammond-Horn study demonstrated the effects of smoking on mortality and cancer risk in 188,000 men observed from 1952 through 1955.
- Cancer Prevention Study I (CPS I), conducted from 1959 through 1972, encompassed 1 million men and women in 25 states and examined a wide range of potential cancer risk factors related to the environment and to individual lifestyles.
- Cancer Prevention Study II (CPS II), one of the largest research studies ever carried out in the United States, was launched in 1982 and is still in progress. This long-term prospective study is examining the habits and exposures of more than 1 million Americans. Causes of death among these people over subsequent years are being studied to learn how lifestyles and environmental factors affect the development of cancer.

Over 77,000 volunteers enrolled 1.2 million men and women in CPS II. These volunteer researchers distributed a four-page confidential questionnaire to participants who were asked about their exposures to certain environmental conditions, their personal history of disease, and their lifestyles.

Many papers have been published from analyses of CPS II questionnaires and follow-up mortality data. One showed

Allocation of American Cancer Society Funds
Based on Total 1991-1992 Budget—$280,339
Detection & Treatment $37,273 9.7%
Prevention $71,123 18.6%
Patient Services $52,487 13.8%
Community Services $27,765 7.3%
Management & General $29,286 7.6%
Fundraising $61,995 16.2%
Research $100,410 26.4%
Figures taken from 1991 Annual Report (in thousands)

massive changes in American smoking habits compared with 23 years earlier in CPS I. Among men, 24% smoked, half as many as in the earlier study. More than twice as many had quit cigarette smoking. Other papers have shown that among women, smokers die of lung cancer at a rate 12 times that of nonsmokers and that men who smoke have an increased risk of myeloid leukemia. Another paper reported that death rates from all causes were 81% higher in obese and underweight people than those of average weight and that exercise was associated with reduced cancer mortality. Most recently, CPS II analyses have shown a relationship between regular aspirin use and reduced risk of fatal colon cancer and the importance of a high-fiber diet and exercise as additional factors associated with a lower colon cancer mortality rate.

Another questionnaire was sent in October, 1992, to 160,000 households participating in CPS II. This questionnaire seeks additional dietary information, with the goal of gaining more specific knowledge about how diet impacts disease.

Public Education

The American Cancer Society's Public Education programs are designed to inform people about cancer, tell them what they can do to protect themselves, and demonstrate related health habits.

The programs focus on two areas:

- cancer prevention which includes tobacco control, the relationship between diet, nutrition, and cancer, and school health education
- the importance and value of periodic, cancer-related checkups and specific early cancer detection tests as recommended by the American Cancer Society.

The Society's Public Education planning strategy emphasizes programs where prevention, risk reduction, and early detection practices realize the greatest return in terms of lives saved.

The Society's Public Education programs are divided into two audience categories: adult and youth. Adults are reached through the worksites, healthsites, and the community. Programs are carried out in a small group setting or one-on-one. All programs offer opportunities for two-way communication. Volunteers are recruited and trained both to promote and to deliver programs. Strategies are selected to reach specific target audiences (e.g. high-risk groups) and materials are developed to assist these strategies.

Examples of adult education include **Taking Control**, which identifies 10 steps to a healthier lifestyle and offers advice for people who want to reduce their chances of getting cancer; **Smart Move**, a single-session stop-smoking program; **Self-Defense**, which explains how a person can work with a health care provider to become familiar with cancer tests and examinations; and **Special Touch**, which explains the facts of breast cancer and early detection techniques.

Youth audiences are primarily reached through the schools. Programs are carried out in the classroom by teachers. The ACS develops age-appropriate curricula that emphasize healthy lifestyles as well as specific cancer prevention and control messages. These curricula can be used to complement existing curricula already being used by teachers or can stand alone.

Examples of youth education include **Starting Free: Good Air for Me**, a smoking prevention program designed for preschoolers; **Early Start to Good Health**, a kit to help K-3 teachers provide a foundation for making healthy

decisions; **Health Myself**, designed for teachers of grades 7-9 to give their students a basis for informed decisions about personal health; **Changing the Course**, designed to provide elementary and secondary students with an opportunity to reduce diet-related risks associated with certain diseases; and **Right Choices**, designed to educate secondary students about cancer and disease.

Detection and Treatment

The Society's Professional Education Department provides health care professionals with the latest information on developments in cancer prevention, early detection, and treatment through national conferences and workshops, audiovisual and print publications, and clinical awards, professorships, and scholarships. Through a network of volunteers who are leaders in the fields of medicine, nursing, social work, dentistry, and other health care disciplines, the Society offers state-of-the-art information on cancer control with the ultimate goal of offering the American public the best possible opportunity to prevent cancer from occurring, to detect it early when it does occur, and to treat it with the best available technology.

Conferences and Workshops

The Detection and Treatment Department offers continuing medical education to physicians and other health care professionals through national conferences and workshops in which leaders in the field of cancer control present the latest information on various preventive strategies, diagnostic techniques, and therapies. The American Cancer Society is accredited by the Accreditation Council for Continuing Medical Education to sponsor continuing medical education. Attendance at these national conferences frequently qualifies for continuing education credits for other disciplines as well.

Audiovisuals, Journals, and Other Publications

Videotapes, slide programs, audiotapes, textbooks, proceedings of conferences and workshops, and booklets on key issues and treatments are examples of the publications the Society offers health care professionals to keep them up-to-date on the latest developments in cancer care. Emphasis is placed on strategies to prevent cancer and methods for detecting it in its earliest stages.

The Society publishes two national journals for health care professionals: *Ca-A Cancer Journal for Clinicians* and *Cancer*, a journal for those specializing in cancer research and in the care of the cancer patient.

Exhibits at National Health Care Meetings

To make health care professionals aware of the publications, services, continuing education offerings, and clinical awards that the Society offers, the Detection and Treatment Department exhibits at national meetings of health care organizations.

Clinical Awards

Leading experts in oncology are supported to promote cancer education in medical, dental, and other appropriate schools through the Professors of Clinical Oncology award. Since the award's inception in 1970, the Society has funded 67 professors.

The National Clinical Awards Program was established in 1948 to provide broad support for oncology training at qualified hospitals and institutions. Over the past 40 years, Regular Clinical Fellowships and Junior Faculty Clinical Fellowships have supported the education of more than 9,600 individuals.

Currently, funds are provided through the following programs:

- The Clinical Oncology Fellowship, which provides unique training opportunities for fellows to expand their expertise in oncology.
- The Clinical Oncology Career Development Award, which is given to outstanding individuals who intend to pursue an academic career in oncology.
- The Oncology Social Work Award, which offers traineeships for oncology social workers committed to research and clinical practice with cancer patients and their families. Each year awards are made to 24 master's and four post-master's candidates.
- The Cancer Control Career Development Award, a new program for primary care physicians created in 1990, is intended for family and general practice physicians who will serve as leaders in teaching, research, and clinical practice.

Nursing Programs

Cancer Nursing News, a free newsletter for nurses provides up-to-date information on cancer, oncology nursing, the ACS, and opportunities in continuing education. Twenty new scholarships are awarded each year to qualified graduate students studying for a master's degree with a specialty in oncology nursing. Scholarships are $8,000 a year for up to two years, based on the student's continuing progress in the graduate program. Professorships in oncology nursing are offered through the chartered Divisions of the Society. These professorships enhance the quality of care of cancer patients by increasing the focus on cancer education in schools of nursing.

Questionable Methods of Cancer Management

The Society monitors and maintains information on unproven methods of cancer management. Information on such questionable treatments is closely reviewed by a committee of volunteer health care professionals, which periodically issues carefully researched position statements

on these various "unconventional" treatments. These position statements are available to physicians, science writers, editors, and the general public. .

Patient Services

In 1992, approximately 718,000 cancer patients were reached through the innovative service and rehabilitation programs of the American Cancer Society.

Service Programs

Community Connection: Resources, Information, and Guidance. This program provides specific information about, and referral to, Society services and other resources in the community to meet the social, psychological, and other support needs of cancer patients and their families.

Transportation. Trained volunteer drivers provide transportation that enables patients to maintain their medical and continuing care programs.

Home Care Items. This program offers supplies and equipment for the comfort and care of the patient at home.

Rehabilitation Programs

Look Good...Feel Better. This program is an opportunity for people undergoing cancer treatment to develop skills to improve their appearance. A program in partnership with the Cosmetic, Toiletry and Fragrance Association and the National Cosmetology Association, it focuses on cosmetic techniques that can help people cope with changes in appearance resulting from cancer treatment.

Reach to Recovery. This program, the largest of the Society's patient-visitor programs, addresses the physical, psychosocial, and cosmetic needs of women who have or have had breast cancer. Carefully selected and trained volunteer visitors provide support and information. In addition, literature and services to help husbands, children, and friends of breast cancer patients are available.

CanSurmount. This is a short-term visitor program for cancer patients and their families. One-to-one visits by a carefully selected and trained volunteer who has experienced the same type of cancer offer personal, emotional, and social support.

Laryngectomy Rehabilitation. Spearheaded by the International Association of Laryngectomees, this program is coordinated through more than 300 clubs. Laryngectomee visitors provide pre- and/or postoperative support to patients who undergo removal of the larynx.

Ostomy Rehabilitation. Some patients with intestinal or urinary cancers must have abdominal ostomies (surgically constructed openings for elimination of body wastes). Trained volunteers who have experienced this same type of surgery offer help on a one-to-one basis. Cooperating with the United Ostomy Association and enterostomal therapists, patients are assisted in their physical and psychological adjustment.

Patient and Family Education Programs

The Society sponsors group and individual education programs, distributes pamphlets and booklets and provides audiovisual presentations for patients of all ages and their families to help them understand and deal with the complexities of the disease.

I Can Cope. Information is provided on cancer and its treatments, nutrition, resource availability, and other issues of concern to cancer patients and their families.

Group Support Programs

A variety of support and self-help groups for patients, families, and friends offered according to each Division's needs and resources. Some programs may be co-sponsored with other community agencies or organizations.

Cancer and the Socioeconomically Disadvantaged

Since 1988, the American Cancer Society has challenged itself to place an increasingly larger emphasis on reaching and serving the poor. In fact, the core programs recommended for the Society's 3,400 local Units call for special focus on the socioeconomically disadvantaged.

The ACS has funded over 100 community demonstration projects to provide cancer education messages and programs to the poor. These programs include cancer screening and education programs, transportation programs, and patient service support. Overall, approximately 10 to 12 million adults in socioeconomically disadvantaged populations are reached annually with direct public education programs. The ACS has created working relationships with dozens of community agencies that serve the poor.

Scientific and medical research grants currently in effect and directly related to the poor totaled more than $1.5 million last year. In addition, the American Cancer Society is funding six multi-million dollar Prevention, Education, and Detection Demonstration Projects for the socioeconomically disadvantaged in some of the nation's poorest areas: Miami—targeting urban Hispanics and black women for mammography and Pap screenings; West Virginia—targeting white, rural, poor women for mammography and Pap screenings; Oakland, CA—targeting inner-city blacks for all cancer sites; Atlanta—targeting inner-city black women for mammography and Pap screening; Wisconsin—targeting poor farmers and migrant workers for skin cancer, mammography, Pap tests, and colorectal and prostate screenings.

Summary of Research Grants & Fellowships Awarded by the American Cancer Society (National and Division)
During the Fiscal Year Ending August 31, 1992 (Subject to Audit)

Albert Einstein College of Medicine, Bronx, NY	(10)	$3,142,000	Medical College of Ohio, Toledo	(2)	$ 290,500
Albany Medical College, Albany, NY	(1)	98,500	Medical Research Council, Cambridge, EN	(2)	107,200
Alliance Univ. for Cancer Research, Philadelphia, PA	(1)	160,000	Memorial Sloan-Kettering Cancer Ctr., New York, NY	(19)	1,731,300
Arizona State Univ., Tempe	(1)	208,000	Miami Univ., Oxford, OH	(1)	83,000
Arizona Univ., Tucson	(4)	592,000	Michigan Cancer Foundation, Detroit	(4)	523,000
Baylor College of Medicine, Houston, TX	(4)	389,500	Michigan State Univ., East Lansing	(3)	368,000
Beth Israel Hospital, Boston, MA	(3)	508,000	Montana State Univ., Bozeman	(1)	50,000
Boston Univ., Boston, MA	(3)	232,000	Montefiore Medical Center, Bronx, NY	(1)	200,000
Bowman Gray Sch. of Medicine, Winston-Salem, NC	(2)	91,000	Mt. Sinai Hospital Research Inst., Toronto, CA	(1)	78,500
Brandeis Univ., Waltham, MA	(1)	104,000	Mt. Sinai Medical Center, New York, NY	(2)	528,000
Brigham & Women's Hospital, Boston, MA	(4)	725,000	Nebraska Academy of Sciences, Washington, DC	(1)	102,000
Brigham Young Univ., Provo, UT	(1)	600,000	Natl. Jewish Hospital & Research Ctr., Denver, CO	(1)	90,000
Brown Univ., Providence, RI	(4)	609,100	New England Deaconess Hospital, Boston, MA	(2)	310,000
California Inst. of Technology, Pasadena	(1)	213,000	New Jersey Medical School, Newark	(1)	102,000
California Inst. of Technology Res., La Jolla	(1)	84,000	New York Medical College, Valhalla	(1)	93,000
Carnegie Institution of Washington, Baltimore, MD	(2)	72,536	New York Univ., NYC	(13)	1,586,000
Carnegie Mellon Univ., Pittsburgh, PA	(1)	604,000	Northwest Cancer Institute, Bellevue, WA	(1)	78,000
Case Western Reserve Univ., Cleveland, OH	(4)	208,000	North Carolina State Univ., Raleigh	(1)	53,000
Children's Hospital, Boston, MA	(1)	127,500	North Shore Univ. Hospital, Manhasset, NY	(1)	83,500
Children's Hospital of Los Angeles, Los Angeles, CA	(2)	98,500	Northwestern Univ., Evanston, IL	(1)	200,000
City of Hope National Medical Ctr., Duarte, CA	(1)	473,500	Northwestern Univ., Chicago, IL	(9)	1,044,000
Cold Spring Harbor Lab., Cold Spring Harbor, NY	(7)	164,000	Oak Ridge Assoc. Univ., TN	(1)	118,000
Colorado State Univ., Fort Collins, CO	(1)	1,376,000	Ohio State Univ., Columbus	(4)	406,000
Columbia Univ., New York, NY	(10)	634,900	Oklahoma Medical Res. Fdn., Oklahoma City	(1)	95,000
Cornell Univ., New York, NY	(4)	272,000	Oregon Health Sciences Univ., Portland	(3)	300,000
Ctr. for Molecular Medicine & Immunol., Newark, NJ	(1)	1,337,000	Oregon State Univ., Corvallis	(3)	189,000
Dana-Farber Cancer Institute, Boston, MA	(11)	1,346,101	Pennsylvania State Univ., Hershey	(4)	398,000
Dartmouth College, Hanover, NH	(7)	64,000	Pittsburgh Cancer Institute, Pittsburgh, PA	(1)	104,000
Drexel Univ., Philadelphia, PA	(2)	1,438,126	Princeton Univ., Princeton, NJ	(18)	1,928,000
Duke Univ., Durham, NC	(13)	108,000	Public Health Res. Inst. at New York, NYC	(1)	84,000
Eleanor Roosevelt Inst. for Cancer Res., Denver, CO	(1)	84,000	Purdue Univ., West Lafayette, IN	(3)	197,000
East Carolina Univ., Greenville, NC	(1)	1,294,500	Reed College, Portland, OR	(1)	53,000
Emory Univ., Atlanta, GA	(18)	108,000	Rochester Univ., New York, NY	(2)	266,000
Florida State Univ., Tallahassee	(1)	10,000	Rockefeller Univ., New York, NY	(2)	123,000
Foundation for Advanced Research, Washington, DC	(1)	1,151,500	Roger Williams Cancer Center, Providence, RI	(1)	83,500
Fox Chase Cancer Center, Philadelphia, PA	(8)	908,500	Roswell Park Memorial Institute, Buffalo, NY	(8)	843,000
Fred Hutchinson Cancer Res. Center, Seattle, WA	(6)	799,000	Ruth Pleasant-Simon Lunn Inst., Ctr., Chicago, IL	(3)	419,000
Georgetown Univ., Washington, DC	(4)	2,384,500	Rutgers, State Univ. at New Jersey, Piscataway	(4)	603,000
Harvard Medical School, Boston, MA	(11)	471,710	State Univ. at New York (SUNY) at Binghamton	(1)	59,573
Harvard Univ., Cambridge, MA	(3)	179,000	State Univ. at New York (SUNY) at Brockport	(2)	234,000
Henry Ford Hospital, Detroit, MI	(1)	725,000	State Univ. at New York (SUNY) at Stony Brook	(7)	522,000
Hunter College (CUNY), New York, NY	(1)	108,000	Stella Institute, Los Altos, CA	(4)	606,360
Indiana Univ., Bloomington	(2)	344,000	San Diego State Univ., CA	(1)	108,000
Indiana Univ., Bloomington	(4)	705,000	Scripps Clinic & Research Foundation, La Jolla, CA	(4)	439,000
Intl. Union Against Cancer, Geneva, Switzerland	(2)	168,000	Seattle Biomedical Research Inst., WA	(1)	216,000
Iowa State Univ., Ames	(1)	3,228,000	Southwest Foundation Biomed. Res., San Antonio, TX	(1)	84,000
Johns Hopkins Univ., Baltimore, MD	(29)	92,000	SRI International, Menlo Park, CA	(1)	56,000
Kansas State Univ., Manhattan	(1)	80,000	St. Jude Children's Research Hospital, Memphis, TN	(1)	104,500
Karpinska Institute, Stockholm, Sweden	(1)	179,000	St. Louis Univ., St. Louis, MO	(2)	162,000
La Jolla Cancer Research Foundation, La Jolla, CA	(1)	56,000	Stanford Univ., Stanford, CA	(19)	1,727,200
Louisiana State Univ. Med. Ctr., New Orleans, LA	(1)	79,000	Temple Univ., Philadelphia, PA	(1)	178,000
Laboratory of Molecular Genetics, Strasbourg, FR	(1)	56,000	Texas A & M Univ., College Station, TX	(1)	83,500
Lehigh Univ., Bethlehem, PA	(1)	98,500	Texas Col. of Osteopathic Med., Fort Worth	(1)	98,500
Loyola Univ. at Chicago, Maywood, IL	(3)	398,000	The Monell Chemical Senses Center, Philadelphia, PA	(2)	603,000
Massachusetts General Hospital, Charlestown	(10)	1,151,000	The Wistar Institute, Philadelphia, PA	(2)	304,000
Massachusetts Inst. of Technology, Cambridge	(11)	813,500	The Methodist Hospital, Houston, TX	(1)	79,000
Mayo Clinic Foundation, Rochester, MN	(1)	223,000	Thomas Jefferson Univ., Philadelphia, PA	(6)	734,000
McGill Univ., Montreal, CA	(1)	78,000	Tufts Univ., Boston, MA	(1)	98,500
Melanoma Research Inst., Great Falls, MT	(1)	103,000	UMDNJ-Robert Wood Johnson Medical School, NJ	(4)	268,500
Medical College of Virginia, Richmond	(3)	368,000	Univ. City Science Center, Philadelphia, PA	(1)	103,000
Medical College of Wisconsin, Milwaukee	(4)	369,000	Univ. of Alabama at Birmingham	(6)	421,000
Medical College of Pennsylvania, Philadelphia	(1)	98,000	Univ. of Arizona, Tucson	(3)	268,500
Medical Univ. of South Carolina, Charleston	(1)	79,000	Univ. of Arkansas for Med. Sciences, Little Rock	(1)	65,000
Medical Biology Institute, La Jolla, CA	(2)	199,000	Univ. of California at Berkeley	(16)	1,378,560
Medical College of Georgia, Augusta	(1)	160,000	Univ. of California at Davis	(8)	891,600
			Univ. of California at Irvine	(14)	1,418,223
			Univ. of California at Los Angeles	(7)	729,000

Univ. of California at Riverside	(2)	$ 252,000
Univ. of California at Santa Barbara	(1)	121,000
Univ. of California at San Francisco	(28)	2,793,060
Univ. of California at San Diego	(11)	1,272,000
Univ. of California at Santa Cruz	(1)	98,500
Univ. of Chicago, IL	(4)	671,000
Univ. of Cincinnati, OH	(2)	228,000
Univ. of Colorado Hlth. Sci. Center, Denver	(9)	1,268,000
Univ. of Colorado, Boulder	(1)	73,000
Univ. of Connecticut, Farmington	(3)	278,000
Univ. of Florida, Gainesville	(11)	168,500
Univ. of Georgia, Athens	(1)	88,000
Univ. of Hawaii, Honolulu	(3)	288,000
Univ. of Houston, TX	(1)	34,825
Univ. of Iowa, Iowa City	(3)	184,000
Univ. of Kansas, Lawrence	(1)	134,000
Univ. of Kentucky, Lexington	(3)	671,316
Univ. of Louisville, KY	(1)	44,000
Univ. of Illinois, Chicago	(3)	284,000
Univ. of Maryland, Baltimore	(4)	447,000
Univ. of Medicine & Dent., Cancer, Worcester	(8)	1,047,560
Univ. of Massachusetts, Amherst	(1)	73,000
Univ. of Miami, FL	(4)	368,000
Univ. of Michigan, Ann Arbor	(28)	1,899,631
Univ. of Minnesota, Minneapolis	(8)	930,099
Univ. of New Mexico, Albuquerque	(3)	468,000
Univ. of North Carolina, Chapel Hill	(27)	1,643,223
Univ. of Medicine and Dent., Cancer, Camden	(3)	1,040,000
Univ. of Oregon, Eugene	(3)	281,692
Univ. of Pennsylvania, Philadelphia	(23)	1,357,373
Univ. of Pittsburgh, PA	(9)	1,752,360
Univ. of Rhode Island, Kingston	(1)	203,000
Univ. of Rochester, NY	(8)	1,006,000
Univ. of South Florida, Tampa	(1)	98,500
Univ. of Southern California, Los Angeles	(13)	723,500
Univ. of Tennessee, Memphis	(3)	363,000
Univ. of Tennessee, Memphis	(3)	413,000
Univ. of Texas MD Anderson Ca. Ctr., Houston	(9)	1,079,000
Univ. of Texas Med. Br., Galveston	(2)	230,000
Univ. of Texas Southwestern Med. Ctr. at Dallas	(13)	1,304,500
Univ. of Texas Hlth. Sci. Ctr. at Houston	(3)	128,000
Univ. of Texas Hlth. Sci. Ctr. at San Antonio	(3)	669,160
Univ. of Utah, Salt Lake City	(4)	932,000
Univ. of Vermont, Burlington	(4)	468,500
Univ. of Virginia, Charlottesville	(19)	1,854,100
Univ. of Washington, Seattle	(3)	398,500
Univ. of Wisconsin, Madison	(13)	1,465,500
Univ. of Wisconsin, Milwaukee	(1)	99,000
Univ. of Wyoming, Laramie	(1)	98,500
Utah State Univ., Logan, UT	(1)	199,000
VA Medical Center, Minneapolis, MN	(1)	52,192
Vanderbilt Univ., Nashville, TN	(4)	532,000
Virginia Mason Research Center, Seattle, WA	(2)	173,000
Washington State Univ., Pullman	(1)	53,000
Washington Univ., St Louis, MO	(7)	884,000
Wayne State Univ., Detroit, MI	(5)	663,500
Wesleyan Univ., Middletown, CT	(2)	168,000
West Virginia Univ., Morgantown, WV	(1)	56,000
Whitehead Institute, Cambridge, MA	(3)	272,000
Wistar Institute, Philadelphia, PA	(4)	736,000
Worcester Foundation for Exp. Biol., Shrewsbury, MA	(1)	78,000
Yale Univ., New Haven, CT	(28)	2,538,125
	(888)	$94,264,694
Endowed		$ 3,227,963
Research Total		$97,539,657

Note: Numbers in parentheses indicate number of grants per institution.

Cancer Centers

The institutions listed have been recognized as Cancer Centers by the National Cancer Institute. These centers have been rigorously reviewed by the National Cancer Advisory Board. They receive financial support from the National Cancer Institute, the American Cancer Society and many other sources.

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Arizona Cancer Center*
University of Arizona
(602) 626-7925

CALIFORNIA
Kenneth Norris, Jr. Comprehensive Cancer Center*
University of Southern California
(213) 224-6600

Jonsson Comprehensive Cancer Center*
University of California at Los Angeles
(213) 825-5268

La Jolla Cancer Research Foundation
(619) 455-6480

UCSD Cancer Center
University of California at San Diego Medical Center
(619) 543-3325

Beckman Research Institute City of Hope
(818) 359-8111

Armand Hammer Center for Cancer Biology
Salk Institute
(619) 453-4100

COLORADO
University of Colorado Cancer Center
University of Colorado Health Sciences Center
(303) 270-3007

CONNECTICUT
Yale University Comprehensive Cancer Center*
(203) 785-4095

DISTRICT OF COLUMBIA
Lombardi Cancer Research Center*
Georgetown University Medical Center
(202) 687-2100

FLORIDA
Sylvester Comprehensive Cancer Center*
University of Miami Medical School
(305) 548-4900

ILLINOIS
Illinois Cancer Center
(312) 996-5910

University of Chicago Cancer Research Center
(312) 702-6180

INDIANA
Purdue University Cancer Research Center
(317) 494-8139

MAINE
The Jackson Laboratory
(207) 288-3371

MARYLAND
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Dana Farber Cancer Institute*
(617) 732-3000

Worcester Foundation for Experimental Biology
(508) 842-8921

Massachusetts Institute of Technology
Center for Cancer Research
(617) 253-6421

MICHIGAN
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(313) 745-8870

University of Michigan Cancer Center
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NEW YORK
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Cancer Research Center
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American Health Foundation
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Lineberger Cancer Research Center*
University of North Carolina
(919) 966-3036

Comprehensive Cancer Center*
Wake Forest University
Bowman Gray School of Medicine
(919) 716-4464

OHIO
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Ohio State University
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(614) 293-4478

Cancer Research Center
Case Western Reserve University
(216) 844-8453

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(215) 728-2761

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(215) 662-6334

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(215) 898-3926

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(215) 221-4301

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(401) 456-2661

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(615) 327-6315

St. Jude Children's Research Hospital
(901) 522-0301

TEXAS
M.D. Anderson Cancer Center*
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Institute for Cancer Research and Care
(512) 416-5590

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University of Utah Health Sciences Center
(801) 581-4048

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(802) 656-4414

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Massey Cancer Center
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(804) 924-1948

WASHINGTON
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(206) 667-4392

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(608) 262-2177

*Indicates Comprehensive Cancer Center.

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(813) 253-0541

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Atlanta, Georgia 30308
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North Brunswick, New Jersey 08902
(908) 297-8900

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Albuquerque, New Mexico 87110
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The American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer, and diminishing suffering from cancer through research, education, and service.

National Headquarters: American Cancer Society, Inc., 1599 Clifton Road N.E., Atlanta, GA 30329-4251

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93-40004-No. 9008.93

The National Breast and Cervical Cancer Early Detection Program

AT-A-GLANCE

1992–1993

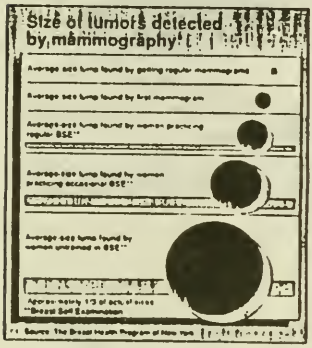
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service

CDC

Breast and Cervical Cancers

In this decade, an estimated 2 million women will learn they have breast or cervical cancer, and more than half a million women are expected to lose their lives. A disproportionate number of these deaths will occur among women of low income.

Mammography screening remains the single most effective method of detecting breast cancer in its early, most curable stages. The Papanicolaou (or Pap) test, introduced in the 1940s, provides the means to prevent virtually all deaths from cervical cancer.



Congress Responds

Congress recognized the lifesaving potential offered through early detection when it passed The Breast and Cervical Cancer Mortality Prevention Act. Enacted in 1990, this law forms the foundation for a long-term, comprehensive national public health approach. In creating this program, the United States joins other countries worldwide that have established national cancer screening programs as a top public health priority.

Program Elements

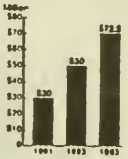
In 1993, CDC entered into the third year of this program, which will direct $72.5 million to support state health agencies in developing effective public health support systems for the early detection process. The CDC and the states work together to:

- Establish, expand, or improve screening services in communities with women at risk.
- Deliver education programs to send the public clear, consistent, and culturally sensitive messages about the lifesaving value of screening.
- Deliver education programs for physicians and other health care professionals to improve skills related to early detection services.
- Improve quality assurance measures to ensure adherence to standards and guidelines related to screening mammography and cervical cytology.
- Establish surveillance and evaluation systems to determine where prevention efforts have the most impact.
- Establish state-level cancer control coalitions that include key public, private, and voluntary organizations.

Women Served

All women at risk for breast and cervical cancers are served according to the national consensus guidelines for age and frequency of screening. Program efforts are emphasized (and direct services provided) for older, low-income, underinsured, and uninsured women.

Funding Timeline



- $30 million appropriated in 1991 by The Breast and Cervical Cancer Mortality Prevention Act of 1990
- $50 million appropriated in 1992.
- A $22.5 million increase brings the current funding level to $72.5 million, supporting program activity in 30 states

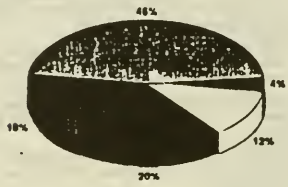
National Partners

To stimulate more aggressive action in breast and cervical cancer early detection nationwide, CDC has provided the leadership and coordination of a unique public/private consortium representing federal, professional, voluntary, and community-based organizations. Key partners include:

- AMC Cancer Research Center
- American Academy of Physician Assistants
- American Cancer Society
- American College of Physicians

National Partners continued on back page

Percentage of Screening Mammograms*
Provided to Participants, by Race/Ethnicity–United States. July 1991–July 1992 (n=14,449)

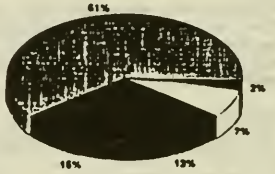


Race/Ethnicity

White, Non-Hispanic
Black
White, Hispanic
Other/Unknown
Aleut/Esk/Am Ind

* Includes California, Colorado, Maryland, Michigan, Minnesota, New Mexico, South Carolina, Texas, and West Virginia

Percentage of Papanicolaou Tests*
Provided to Participants, by Race/Ethnicity–United States. July 1991–July 1992 (n=23,585)



Race/Ethnicity

White, Non-Hispanic
Black
White, Hispanic
Other/Unknown
Aleut/Esk/Am Ind

* Includes California, Colorado, Maryland, Michigan, Minnesota, New Mexico, South Carolina, Texas, and West Virginia

1992 Comprehensive Screening Programs:

California
Colorado
Maryland
Michigan
Minnesota
Missouri
Nebraska
New Mexico
North Carolina
South Carolina
Texas
West Virginia

1992 Capacity Building Programs*:

Alaska
Arizona
Arkansas
Connecticut
Georgia
Illinois
Indiana
Iowa
Maine
Massachusetts
New York
Ohio
Oregon
Pennsylvania
Rhode Island
Vermont
Washington
Wisconsin

* *In planning stages.*

continued from National Partners

- American College of Radiology
- American Medical Women's Association
- American Nurses Association
- American Public Health Association
- Association of State and Territorial Chronic Disease Program Directors
- Association of State and Territorial Directors of Public Health Education
- Association of State and Territorial Health Officials
- Conference of Radiation Control Program Directors
- Food and Drug Administration
- Health Care Financing Administration
- Health Resources and Services Administration
- ICI Pharmaceuticals Group
- Indian Health Service
- Jacobs Institute of Women's Health
- National Alliance of Breast Cancer Organizations
- National Association of County Health Officials
- National Cancer Institute
- National Medical Association
- Young Women's Christian Association

Recommended Frequency for Breast Cancer Screening

In 1989, 11 national organizations developed standardized breast cancer screening guidelines for women over age 40:

- Clinical examination of the breast and mammography are the basic detection methods. The examinations are complementary, and both are necessary to achieve maximum detection rates
- The screening process should begin at age 40 and consist of an annual clinical examination with screening mammography performed at 1- to 2-year intervals.
- Beginning at age 50, both clinical examination and mammography should be performed annually.

These recommendations apply only to women without signs or symptoms of breast cancer; the frequency and type of examination will vary for the individual with symptoms and should by determined by the responsible physician.

Recommended Frequency for Cervical Cancer Screening

- An annual Pap test and pelvic examination in all women who are, or have been, sexually active or who have reached the age of 18.
- After three or more consecutive satisfactory, annual examinations the Pap test may be performed less frequently, at the discretion of the health care provider.

Estimated Number of New Breast Cancer Cases and Deaths, by State: United States, 1992

State	New Cases	Deaths
Alabama	2,700	700
Alaska	175	50
Arizona	2,400	600
Arkansas	1,700	425
California	19,000	4,800
Colorado	1,800	475
Connecticut	2,700	700
Delaware	600	175
District of Columbia	600	150
Florida	11,200	2,900
Georgia	4,400	1,100
Hawaii	425	125
Idaho	500	125
Illinois	8,500	2,200
Indiana	4,100	1,100
Iowa	2,300	600
Kansas	1,800	450
Kentucky	2,400	650
Louisiana	2,600	650
Maine	850	225
Maryland	3,500	900
Massachusetts	5,400	1,400
Michigan	8,800	1,700
Minnesota	3,200	800
Mississippi	1,700	425
Missouri	3,900	1,000
Montana	450	125
Nebraska	1,200	300
Nevada	750	200
New Hampshire	900	225
New Jersey	6,700	1,700
New Mexico	800	225
New York	18,900	4,000
North Carolina	3,100	1,300
North Dakota	425	100
Ohio	8,800	2,200
Oklahoma	2,100	550
Oregon	2,100	550
Pennsylvania	10,700	2,800
Rhode Island	1,000	250
South Carolina	2,300	550
South Dakota	550	150
Tennessee	3,600	900
Texas	8,700	2,200
Utah	700	200
Vermont	475	125
Virginia	4,300	1,100
Washington	3,200	800
West Virginia	1,400	350
Wisconsin	3,500	900
Wyoming	300	75
Total	180,000	46,000

Source: American Cancer Society

For more information, please contact the Centers for Disease Control and Prevention, Mail Stop K 52, 4770 Buford Highway NE., Atlanta, GA 30341-3724, (404) 488-4751.

Texas Breast and Cervical Cancer Control Program

July 15, 1993

Mister/Madame Chairman and honorable members of the Labor and Human Resources Committee, Subcommittee on Aging, I am Margaret Méndez, Director for the Texas Department of Health Breast and Cervical Cancer Control Program. Thank you for the opportunity to speak today on behalf of Texans. I am pleased to share with you our experience with the Breast and Cervical Cancer Control Program, a program, as you know, funded by the Centers for Disease Control and Prevention (CDC).

Background

Texas was selected in 1991, as one of the first eight states to participate in the Program. The Program covers the cost of screening and some diagnostic services for breast and cervical cancer. The Program is unique from other chronic disease programs in the breadth and complexity of its requirements. Essential components cover far more than just screening and diagnosis. In addition, requirements include tracking the progress of every woman screened in order to ensure appropriate follow-up care, collecting and analyzing detailed demographic, historical, and medical outcome data for every woman screened, enforcing stringent quality assurance standards for health care providers, offering professional education opportunities to local staff, and providing public information. Our experience thus far has been challenging and rewarding.

Support for the Program has been crucial from Day One. In Texas, many organizations helped get the Program off the ground, each offering unique perspectives and resources to make the program work---from the writing of the initial application all the way through the current implementation.

Through this early meeting of minds, some strategies were developed for implementing the Program as quickly as possible:

- First, we prioritized areas of the State having the greatest need for services for high risk women;
- Second, we sought local health care providers who offered comprehensive chronic disease services in order for women to have access to complete health care;
- Then, we decided to use local providers with access to our target population -

women who live below 200 percent of the federal poverty level, women age 40 or older, and minority women; and

- We selected providers with experience in gaining access to diagnostic and treatment resources.

Screening began within three months after the award from CDC.

We now contract with 35 local health care organizations to deliver services at more than 300 delivery sites throughout Texas.

In addition to screening and follow-up, many other interrelated activities contribute to improving the quality and accessibility of services for Texas women. For instance:

- Quality assurance is a cornerstone of this Program. The proportion of mammography facilities accredited by the American College of Radiology and used by our providers shot up 50 percent from our first year of operation to the second year.
- A door-to-door survey on knowledge and attitudes about breast and cervical cancer, as well as on early detection health habits among women in our target population was completed last week. Analysis is in progress. The survey will provide baseline data for future evaluation of Program effectiveness. Results also will provide a basis for developing health promotion activities. Materials developed for public information campaigns this year will reflect survey findings.
- The Program supports numerous professional education activities. The professional education needs of local providers were surveyed. Many health care professionals have participated in both clinical and didactic training opportunities offered throughout the State.

Preliminary Findings

Screening

Since January 1992, through mid-June about 27,000 women were screened for breast cancer. You will note in Figures 1 and 2 about half were Hispanic, about a third were white, and about 20 percent were African American. About half of the breast cancer screenings performed were for women age 40-49, and about half were for women age 50 or older. These

proportions were similar regardless of race. We are especially pleased that half the women screened were older than 50. Many of our colleagues in Texas believe it is most cost effective for us to spend our limited dollars on the age group of women most likely to have cancer. In fact, CDC increasingly emphasizes to us the need to concentrate on this age group.

More than 12,000 women have had cervical cancer screening. The break down by race group is almost identical to the break down in the breast screening category---about half Hispanic, about a third white, and seventeen percent African American. More than half the women getting Pap tests were older than 40; 49 percent were younger than 40. These proportions were similar regardless of race. As with breast cancer screening, we want to increase the proportion of older women screened.

Diagnostic evaluation

About a quarter of the women screened had abnormal results which required either further diagnostic evaluation or short term follow-up. Figures 3 and 4 show that in the last year about 7,000 women needed evaluation or will need evaluation for cancer.

Figures 5 and 6 show that 245 women have been diagnosed with breast or cervical cancer in the last year and a half.

Ways to Improve

Several of the items included in the proposed legislation are consistent with the experience gained in Texas in the last year and a half:

- Private entities are an essential part of the local health care delivery system, particularly in rural areas;
- Medicare has been successfully used in Texas as the basis for reimbursement of services provided to women under the Program;
- With guidance from CDC, the data and surveillance activities conducted for the Program give us a basis for evaluating our providers' success in assuring women receive the recommended follow-up and treatment.

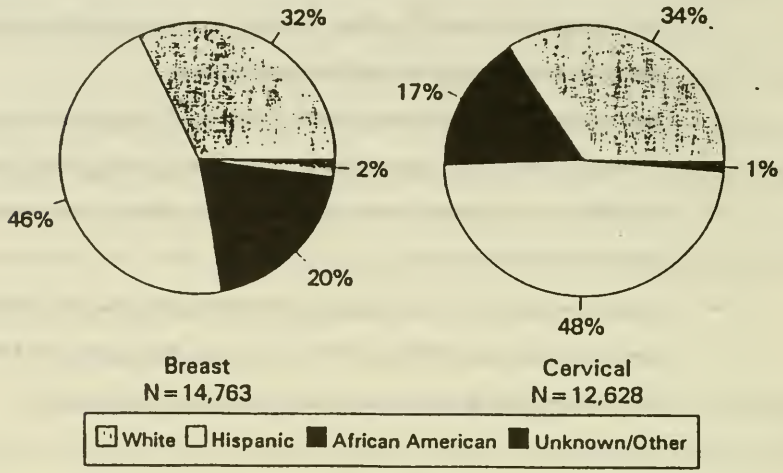
Our accomplishments are significant, but, naturally we still face challenges. We hope to see more flexibility in the Program in order to facilitate our operations to screen women and provide

necessary follow-up care:

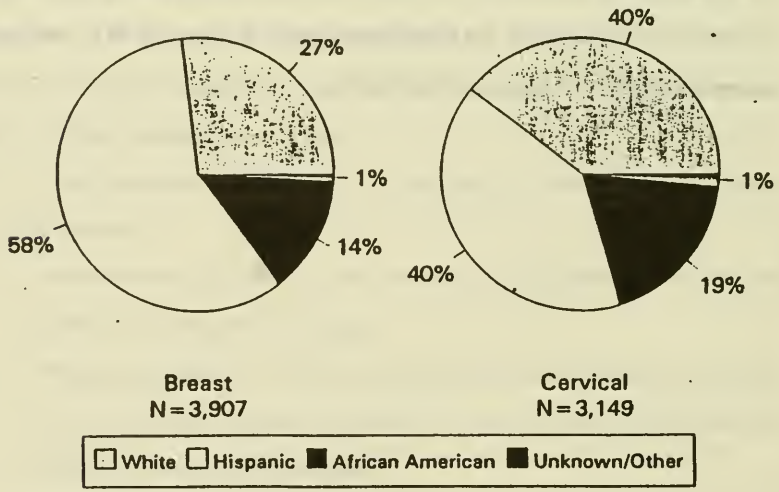
- Finding diagnostic and treatment resources is a time consuming process for most providers. Program providers look to the medical community to set up a network for diagnostic and treatment services. Providers need more flexibility with the mix of services which can be funded under the Program;
- Building capacity in order to serve women in rural areas and also older women is essential; older women are not commonly served in the public health system. In addition, special efforts must be made to reach and rescreen women already served by the Program; and
- Finally, the State of Texas has already met the matching requirement in previous years; it is increasingly difficult to do this every year. Furthermore, the State's ability to match has no relation to the need for services we have in Texas.

We recognize all of these remaining challenges, and know we have only scratched the surface as far as serving the hundreds of thousands of eligible Texas women. While we are thrilled with the early detection of disease in the women screened, there is still a tremendous unmet need both in Texas and in other states. The women screened thus far represent only a fraction of the estimated one and a half million women in Texas age 40 or older who are potentially eligible for Program services (Figure 7).

Texas Women Screened For Breast And Cervical Cancer, June 1993
Figure 1 and Figure 2

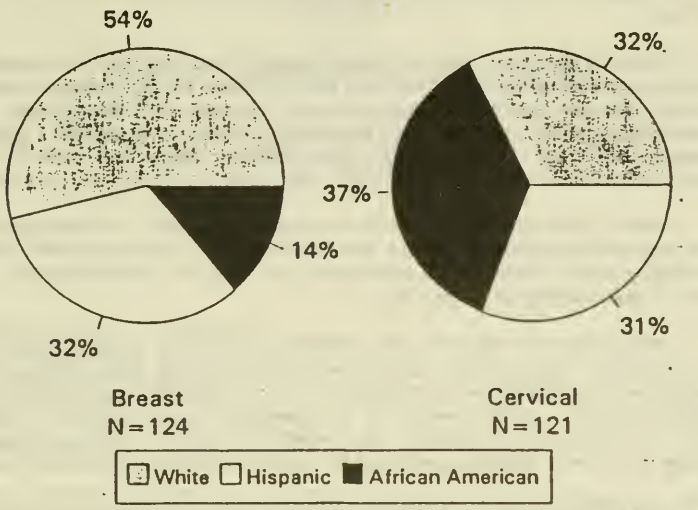


Texas Women Requiring Breast and Cervical Cancer Diagnostic Procedures, June 1993
Figure 3 and Figure 4



Texas Women Diagnosed with Breast and Cervical Cancer, June 1993

Figure 5 and Figure 6



Estimated Number of Women Receiving BCCCP Services By End of Year 2

Figure 7

Source: Texas Department of Health

The source for Figures 1 - 6 is the Texas Breast and Cervical Cancer Control Program database, Texas Department of Health, June 1993.

The source for Figure 7, is the Texas Department of Human Services, the Special Texas Census.

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Attachment A

A few of the women who make the Texas Breast and Cervical Cancer Control Program what it is.

- Esmeralda Morin is 42 years old, lives in Seguin, Texas, and has a low income. A few months back, she came to a local clinic for a Pap test. Since she was already on-hand for the Pap, her doctor gave her a clinical breast exam too. Esmeralda never dreamed there would be a lump in one of her breasts. But, that's what the doctor found. She then got a mammogram through the Breast and Cervical Cancer Control Program. Cancer was found, and she was treated. Esmeralda says if not for the Program, she would never have had a mammogram.

- Sandra Cook is 39 and a mother of four in Round Rock, Texas. She learned that she had severe dysplasia after getting a Pap test under the Program. She was surprised and scared. After finding out her results, she got treated and is now doing fine. Sandra promptly arranged for her 19 year old daughter to get a Pap.

- Bernice Durio is 62 and lives on a fixed income in Austin, Texas. She has no health insurance and until recently hadn't had a mammogram in four years. She says they were simply too expensive. She heard about our Program's no-cost services when a nurse talked to women at Bernice's church. Bernice went in for a mammogram, cancer was found, and she was treated. She says she has no idea how long it would have been before she would have noticed the lump on her own. Bernice recently had her second breast removed because of cancer.

- Peggy Collins is in her 40's and lives in Vidor, Texas. Peggy went to the University of Texas Medical Branch clinic in Beaumont after her boyfriend heard a radio announcement about the Program. He made an appointment for her. The clinic nurse felt a lump when she examined Peggy's breast. The nurse scheduled Peggy for a fine needle aspiration diagnostic procedure. The lump was cancerous. Peggy underwent a lumpectomy, mastectomy, reconstructive surgery, and chemotherapy. She has since served as a spokesperson for the Program, participating in numerous news interviews and encouraging other women to get their breasts checked for cancer.

Texas Department of Health

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Robert A. MacLean, M.D.
Deputy Commissioner

July 26, 1993

The Honorable Barbara A. Mikulski
United States Senate
Hart Senate Office Bldg., Ste. 709
Washington, DC 20510-2003

Dear Senator Mikulski:

Thank you for the opportunity to speak before the Subcommittee on Aging regarding the reauthorization of the Centers for Disease Control and Prevention Breast and Cervical Cancer Prevention Program.

I am enclosing a revised copy of the written testimony submitted for the hearing. The revised testimony adds the words "..and cervical.." to page three, the first paragraph under "Screening."

Thank you again and for your leadership in this area. I would be pleased to provide additional information regarding the Texas experience with this program at your request.

Sincerely,

Margaret C. Méndez
Director
Breast and Cervical Cancer Control Program
Chronic Disease Prevention Division

[Whereupon, at 12:00 p.m., the subcommittee was adjourned.]

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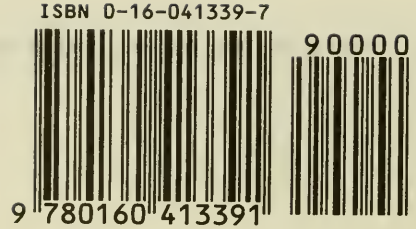
ISBN 0-16-041339-7